Children Affected by HIV/AIDS

KHANA
Khmer HIV/AIDS NGO Alliance

Appraisal of Needs and Resources in Cambodia

Summary Report

Phnom Penh January-May 2000

Supported by USAID through the International HIV/AIDS Alliance

International HIV/AIDS Alliance

USAID

Contents

1 EXECUTIVE SUMMARY

Khana Appraisal of Needs and Resources for Children Affected by HIV/AIDS in Cambodia

1.1 Context

1.1.1 Cambodia is one of the poorest countries in the world, trying to recover from three decades of turmoil and conflict. With over 50% of the population under the age of 18, Cambodia has a high dependency ratio. Since government spending is still focussed on the military, and the NGO sector still in its infancy, there are few resources beyond families and communities to feed, educate and care for the more than 5 million Cambodian children and young people. The situation of vulnerable children is being compounded by one of the most serious HIV epidemics in the region.

1.1.2 Results from the 1999 Surveillance Survey indicate that approximately 170,000 Cambodians are now infected with HIV, giving an adult HIV prevalence rate of around 3.5%. The majority of these people are either parents, or at an age where their economic productivity is at it's highest and is being used to support other family members. Consequently with sickness and eventual death of carers and supporters, a great number of children are, and will be adversely affected by AIDS in Cambodia.

1.1.3 Cambodia along with Thailand currently has the highest proportion of AIDS orphans (one or both parents dead) in Asia. It is estimated that by 2005, approximately 3% of all children under the age of 15 in Cambodia will have been orphaned by AIDS. It is also predicted that by the end of 2000 over 5% of all HIV infections are likely to be in children under 18 years and that some 7,500 children will have died of AIDS.

1.1.4 Although concerted efforts are being made in prevention and care,most Cambodians still do not have access to HIV counselling and testing, to safe blood, or to drugs for HIV-related infections. Poor families spend over 25% of their incomes on basic health care, and the biggest cause of landlessness is the sale of land to cope with a health crisis in the family. Although Cambodia is a signatory to the UN Convention on the Rights of

the Child, laws and systems to enforce these rights and for protecting children are still being developed. Insecurity due to conflict is still an issue in some areas.

1.1.5 The Khmer HIV/AIDS NGO Alliance (Khana) is a national NGO which strengthens the capacity of the local NGO sector to respond effectively to HIV/AIDS/STDs. After four years supporting NGO work on HIV/AIDS prevention and care, project reviews revealed issues relating to children affected by AIDS. In a first step to begin to assist local NGOs to respond to the needs of children affected by AIDS, an appraisal was carried out by Khana with the support of USAID through the International HIV/AIDS Alliance.

1.1.6 The objectives of the appraisal were to determine vulnerability/resilience factors for children, explore how HIV/AIDS-related life events impact on these factors; identify the range of needs specific to children affected by AIDS; and to identify existing resources and potential strategies for meeting these needs. A secondary aim was to build the capacity of local NGO staff in participatory appraisal facilitation.

1.2 Methods

1.2.1 Over 900 people participated in the appraisal in 5 locations-Battambang, Kratie, Kompong Thom and Prey Veng Provinces, and Phnom Penh municipality. Locations were chosen for their different levels of INGO/UN agency activity with children, their different levels of Khana partner activity, their different risk factors and because they are all high priority in the National AIDS Strategy.

1.2.2 Of the participants, 55% were children including 413 orphans accessed in rural communities, in children's centres and on the street in urban areas. The adults included community members and leaders, families affected by AIDS, traditional healers, monks, NGO, UN and government staff.

1.2.3 Facilitators used participatory tools to enable participants to determine vulnerability factors for children and then analyse the impact of HIV/AIDS on vulnerability as a result of the sickness and death of one or both parents.

1.2.4 Various techniques were also used to minimise personal disclosure and to help participants to contribute in the manner, and to the level and extent of their choice. Pre-appraisal facilitation training was used to field-test tools and techniques and also to practice recording of discussion topics.

1.2.5 Eighteen facilitators from Khana partner NGOs carried out the appraisal in 6 teams of three each. Two teams were allocated to Phnom Penh, and one team worked in each of the remaining locations.

1.2.6 Analysis of information was carried out both on the spot by groups of participants and by Khana and the NGO facilitators at a subsequent feedback workshop.

1.2.7 Efforts were made to minimise the loss of information through translation from Khmer to English, and to verify the accuracy of reporting.

1.2.8 Limitations of the methodology included the facilitators' reluctance to ask questions when participants were senior government staff, and the fact that it was not possible to access all relevant service providers in the appraisal locations.

1.3 Findings

Participants felt that:

1.3.1 Many factors make children vulnerable in Cambodia, nearly all of them related to poverty. Girls have more vulnerability factors than boys do, and the most vulnerable age is 7-12 years. The most vulnerable children overall are orphans from poor families.

1.3.2 Children affected by HIV/AIDS are exposed to increased factors of vulnerability through high levels of psychosocial stress and stigma.

1.3.3 The impacts of having a parent with HIV-related illness on children are multiple and serious. Families can slide into poverty quickly. Children become carers and income generators, some have to leave home.

1.3.4 After the death of a parent, children can be cheated of land, housing

and other assets. Some may have to work or beg to pay back their parents' debts. Siblings are often split up and are unable to look after one another.

1.3.5 There are limitations to all the options for the care of orphans when both parents have died of AIDS. Grandparents are old and poor and the demographics show proportionately few people of grandparent age; other relatives may treat them as servants; monks have limited resources; children prefer family life to orphanages; life on the street can be dangerous and unhealthy. Adoption and fostering practices are largely unregulated.

1.3.6 Adults often see orphanages as the answer, but children - particularly those in orphanages themselves - disagreed. Overwhelmingly children said they would prefer to live in a family within a community.

1.3.7 The psychosocial impact on children affected by AIDS is very high. Caring for sick parents, coping with grief, being relocated to unfamiliar surroundings, separated from siblings and other support networks can all be traumatic for children. Children may worry that they themselves are infected, that their parents have done something bad, or even feel that they themselves are in some way responsible for what has happened. They may be actively discouraged from talking about a situation where the death of parents is associated with sex. They may be made fun of by other children, or isolated from playing with other children by adults who are misinformed about HIV transmission. Often children in distress behave in ways that may be interpreted as misbehaviour.

1.3.8 Generally, adults don't bother with explanations about why a parent has died if the child is less than 11 years of age. Only a few individuals and organisations in Cambodia have skills to help children grieve, and to help vulnerable children cope with multiple stresses.

1.3.9 Children with HIV are at risk of being denied some basic rights. Poverty and misinformation can result in families thinking it is not worth treating a child with HIV or sending them to school. There is little experience amongst health workers of treating children with HIV/AIDS in Cambodia, and drugs are either expensive or not available.

1.3.10 There are almost no specialist services for children affected by AIDS in Cambodia. Supporting the family through illness and death from

HIV/AIDS is very important to help them not waste precious resources on false cures, and to plan for the future of their children.

1.3.11 Bolstering the existing coping mechanisms of carers and of children themselves is an important goal. This could be done through targeting income generating schemes, credit and savings or by giving direct material support to those caring for children orphaned by AIDS. Children are extremely capable, and orphans can be given skills and opportunities to look after themselves.

1.3.12 Community resources could be enhanced to protect the interests of children affected by AIDS. Widespread HIV/AIDS education is necessary first so that people are not afraid of getting HIV. Role modeling the care and support of people with HIV/AIDS is a good way to help people see there is no risk. Neighbours can help care for the sick and help with practical chores. Community leaders can help solve domestic conflict, including land disputes; negotiate reduced school fees for the poor; encourage community protection of vulnerable children and help keep brothers and sisters together.

1.3.13 It is very important that community programmes of both NGOs and local government integrate HIV/AIDS care and support issues into all activities and into staff training at all levels. To help children, organisations should target families who are economically weak and vulnerable, where parents are chronically sick or the father is absent, and families who are homeless or have no land.

1.3.14 Certain government ministries are key in responding to the needs of children affected by AIDS. In addition to the Ministry of Health, the Ministries of Social Affairs, Women's Affairs and Rural Development have potentially important roles with children affected by AIDS. Government social workers aware of children in families with HIV/AIDS could assist with placement in the community, child protection and continued education. VDCs can facilitate community protection of these children.

1.3.15 Better access to general health care through government health centres would benefit families affected by AIDS, as would expanding home care and national coverage of HIV counselling and testing centres. Planning for children's future is crucial, and increased access to testing and counselling would facilitate this.

1.4 Next Steps

1.4.1 Despite the appraisal process serving to build Khana and their NGO partners' capacity in a number of ways, it is recognised that this appraisal represents only the first in many stages of planning and implementing a response to the issues. Significant gaps exist both in the breadth and depth of the information shared with Khana, particularly with regard to quantitative data showing the scale and spread of need, and to the psychosocial impact of AIDS on children in Cambodia.

1.4.2 Following the appraisal Khana conducted 2 workshops to build NGO and community capacity in working with distressed and vulnerable children. Khana will continue this basic skills building as part of long-term support to NGO partners. Khana will also assist all partner NGOs to carry out participatory project reviews with key community stakeholders in order to determine appropriate short and longer-term strategies to address the needs of children affected by AIDS in their areas of operation.

1.4.3 A six month project is also planned with support from the Alliance to assist some NGOs and their communities to develop and monitor appropriate indicators.

14. 4 Finally, given available capacity and resources, it is not possible for Khana and its partners on their own to achieve widespread impact. Although individual communities, families and children themselves need to be central in decision making and implementation, there is a vital role for the government and other NGOs in upgrading skills and resources. The next logical step would be to carefully study lessons learned in other countries, carry out a systematic situation analysis, and develop and implement a national strategy for children affected by AIDS.

1.4.5 During 2000, Khana will therefore also undertake to disseminate the appraisal and other findings widely, and to advocate for a co-ordinated, multi-sectoral response to the needs of children affected by AIDS in Cambodia.

INTRODUCTION

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Khana is a national Cambodian NGO which strengthens the capacity of the local NGO sector to respond effectively to HIV/AIDS/STDs. It does this by providing grants and intensive technical support to NGO Partners for work in HIV/AIDS prevention[3] *and care. It also helps local NGOs to build organisational capacity and to become stronger advocates for their communities. Khana is a linking organisation of the International HIV/AIDS Alliance*[4]*.*

At the beginning of 2000, Khana supported 33 NGO projects in 13 provinces and 2 municipalities of Cambodia

2.1 About the Report

This report summarises the findings of a qualitative appraisal of needs and resources for children affected by AIDS, carried out by Khana and its NGO Partners during the first part of 2000. The report also includes data and information from other local and international sources, and incorporates lessons learned in other countries. It is intended to promote further action by local NGOs in Cambodia, and to inform the provision of technical assistance in planning services for children affected by AIDS. It is also hoped that it will be of use as a resource to other agencies[5].

2.2 Cambodia National Context

The Kingdom of Cambodia is situated on the Indochina Peninsula and has borders with Thailand, Laos and Viet Nam. It is a country recovering from three decades of conflict, which has left it one of the poorest countries in the world. Cambodia is ranked 73rd out of 78 developing countries in terms of the UN poverty Index.

Government employees including teachers, doctors and uniformed personnel receive very low wages, and have to support themselves through private income generation.

Cambodia has a population of approximately 11.4 million, more than 50% of whom are under 18 years. The adult literacy rate for men is 79.5% and for women 57%. Most Cambodians live in the rural areas where mainly through migration and widowhood, approximately 25% of households are headed by

3 Jerker Edstrom et al. "Ain't Misbehavin': beyond individual behaviour change" PLA Notes 37, IIED. February 2000
4 International HIV/AIDS Alliance. "Report from the Annual Supporters Meeting" 2000
5 We have tried to keep the language of the report suitable for easy translation

Women-heads of households in Cambodia are more vulnerable to poverty because they have less power and fewer opportunities than men.

One of the major causes of landlessness in Cambodia is because families sell land to cope with a health crisis.

The local NGO sector in Cambodia is leading the move for community development. It still lacks skills and resources, and needs a great deal of support to develop.

A larger proportion of rural children do not complete primary school because poverty is higher in the provinces and the distances to school are greater

women. Life expectancy is estimated at 56 years[6]. People gain their livelihood mainly through practicing agriculture, and from a growing informal sector that is almost completely unregulated.

Although there are now serious efforts being made to re-develop Cambodia on all fronts, war has left the country with little in the way of infrastructure and with one of the poorest health systems in the world. Much of health care therefore occurs outside of the government system, and poor people can spend up to 25% of their income on routine treatment. In Cambodia there is no welfare system, 42% of women have never attended school, and law enforcement is problematic. In some areas landmines and personal security are still cause for concern. Only 29% of the population have access to safe drinking water, 15% to electricity.

Despite the first democratic election in 1993, Cambodian politics have remained turbulent and the country's political instability has impeded development. The country is very dependent on external aid, which for the past 2 years has financed all public infrastructure investment by the government. Nevertheless, government structures at both central and local level are intact, and at the lower level leaders can have a strong influence over their communities. There is a growing local NGO sector in Cambodia which is helping communities to redevelop, and there is also an increasing awareness of civil society and of the need to promote human rights[7].

2.3 Children in Cambodia

Cambodia is a signatory to the UN Convention on the Rights of the Child, but is still developing the code of law and the systems which will enforce these rights. More than 50% of Cambodia's population is under the age of 18 years, and the mortality rate for children under 5 is 115 per 1000. Malnutrition amongst children is very high, and a reported 17% of children aged between 10 and 14 years are in full time employment to support themselves and their families. Although 78% of children enroll in primary school, the drop out rate is such that only 40% of these reach grade 5[8]. Only 1 in 4 of the literate

6 UNFPA. "Country Population Assessment: Cambodia" 2000
7 APCASO. "Report of the Consultative Phase of the APCASO HIV/AIDS and Human Rights Project in Cambodia" 2000
8 Kemmerer, Frances. "Resources for Schooling: A Model for Local Accountability". Report for Cambodian Ministry of Education, Youth and Sport, 1999

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2.5 Children Affected by HIV/AIDS in Cambodia

Cambodia and Thailand currently have the highest proportion of AIDS orphans (one or both parents have died) in Asia[13]. With over 50% of Cambodians under the age of 18, children and young people are significantly affected by HIV/AIDS and are likely to become more so. Predictions for the end of 2000 based on surveillance figures from 1998, show that over 5% of all infections are likely to be in children under 18 years and that some 7,500 children will have died of AIDS. Although exact numbers are not yet known, it is estimated that there are currently more than 30,000 children under the age of 15 orphaned by AIDS. This is seen as a conservative estimate which is likely to increase to around 140,000 (approximately 3% of all children under the age of 15) by 2005.

The Home-Based Care network of Khana partners, International NGOs and government nurses report a 50% increase in numbers of children living in families with HIV/AIDS over the past 6 months. Numbers of HIV positive children has also increased by half. Furthermore, from their caseload of 700 patients, an average of 52 children are orphaned by AIDS every month.

A recent AIDS Alliance evaluation of the Cambodian Home Based Care network showed that approximately 21% of the children in families affected by AIDS have had to start working to support the family in the last six months. More than 30% have to provide care and take up other major additional household tasks. 40% of these children have had to leave school, and the same percentage have had to go without basic necessities such as food and clothes. 28% of children have left home or been sent away from home.

Globally, without intervention roughly one third of children born to HIV positive mothers will be HIV infected by the end of their first year. Infection occurs in the womb, during delivery or through breastfeeding. Children may also become infected in all the same ways as adults through contaminated blood transfusions or medical equipment, and through sexual abuse[14]. HIV positive parents in Cambodia who have access to testing must wait the full 15 months before being certain whether their newborn child is infected. This is the age when the child's own antibodies have replaced those of the mother, and a blood test will show whether or not HIV is present in the body. To make sure, a second test should be done after 3 months.

13 Report on the Global HIV/AIDS Epidemic, UNAIDS/WHO, June 1998
14 AHRTAG. "Caring with Confidence: Practical information for health workers who prevent and treat HIV infection in children". Briefing Paper

LESSONS LEARNED FROM OTHER COUNTRIES 3

Lessons learned from Africa and from other countries in the Asia Pacific region suggest that it is vital to integrate services for these children as early on in the epidemic as possible[15,16]. The consequences of not anticipating the needs of children affected by AIDS can result in, increased malnutrition and child mortality; increased stigma attached to HIV/AIDS; increased child labour, exploitation and trafficking; more children abandoned to fend for themselves in extreme poverty on the streets; increased delinquency and child crime; lower rates of literacy; and a greater number of HIV infections in children due to lack of protection and life skills. Generations of children will not learn the skills necessary to contribute to their own development let alone the development of the country. These are also children who will have watched their parents die, suffered multiple bereavement and possibly violence or abuse, without support[17]. Some of them will never have the opportunity to learn appropriate parenting skills with which to raise their own children.

Sometime between the year 2010 and 2020, the global number of children under 15 who have lost their mother or both parents to AIDS will reach 40 million - roughly the size of the population of South Korea

Over the last 10 years or more, interventions for children have been tried, tested and evaluated and lessons have been learned (see Appendix 5 of this report for more detail on interventions)[18].

Dependency ratios which are already high in Cambodia may worsen leading to increasing national poverty through labour and skill shortage and loss of productivity at the household level.

3.1 Lessons about the Needs of Children Affected by AIDS

At the family level, loss of family members due to HIV/AIDS, changes in household and family structure, family dissolution, lost income, impoverishment, lost labour, grief and stress[19,20] have all resulted in creating an environment where it is difficult to care adequately for children's needs.

Children orphaned by AIDS have been shown to be more vulnerable than children orphaned in other ways. Girls have been shown to be more vulnerable than boys[21].

At the community level poverty increases, infrastructure deteriorates, the labour pool is reduced and the community has even fewer resources for self-help.

15 World Bank. "Confronting AIDS: Public Priorities in a Global Epidemic" 1997
16 Ayieka, By. "From Single Parents to Child-Headed Households: The Case of Children Orphaned by AIDS in Kisumu and Siaya Districts" UNDP Study Paper No. 7
17 Lyons, Miriam. "The Impact of HIV and AIDS on Children, Families and Communities: Risks and Realities of Childhood during the HIV Epidemic" UNDP HIV and Development Programme Issues Paper No. 30
18 International HIV/AIDS Alliance. "Orphans and Vulnerable Children (OVC) in Burkina Faso: First Steps in Community Mobilisation" 2000
19 UNICEF "Children Orphaned by AIDS" 1999
20 Donahue, Jill. Williamson, John. "Community Mobilization to Address the Impacts of AIDS: A Review of the COPE II Program in Malawi for the Displaced Children and Orphans Fund" 1998
21 Meegan, Michael. Conroy, Ronan. Tomkins, Andrew. "Identifying emerging needs among AIDS orphans in Kenya". Presentation for the Annual Scientific Review, University of Nairobi, 2000

The impact of HIV/AIDS on children has been shown invariably to be:

- loss of family and identity
- psychological distress
- increased malnutrition
- loss of health care, including immunisation
- increased demands for labour
- fewer opportunities for schooling and education
- loss of inheritance
- forced migration
- homelessness, vagrancy, starvation and crime
- exposure to HIV infection.

3.2 Lessons about Effective Responses

Perhaps more than any other issue, assisting children affected by AIDS requires governments, NGOs and donors from all sectors to collaborate if the response is to be anything but piecemeal and scattered.

With enough resources, it is relatively easy to assist children affected by AIDS. Unfortunately, HIV targets the poorest and most vulnerable where there are few resources to spare. Interventions, therefore, need to be cost effective, as sustainable as possible, and to aim at bolstering existing coping mechanisms in families and communities and amongst children themselves[22,23,24]. Having said this, it is recognised that in countries where there is no government welfare, families and children who are completely destitute will benefit from receiving direct material support - such as food aid - for a period of time.

Lessons from elsewhere show that interventions need to based on national strategy which is well researched, well co-ordinated and well monitored[25]. Underlying principles for projects which help children affected by HIV/AIDS have been shown to include:

- Planning before death
- Listening to children and making their voices heard
- Focusing on child rights
- A high level of community involvement
- Enumeration, and needs assessments
- Targeting assistance to the most needy

22 Lee, Tim et al. "Report of a participatory self-evaluation of the FACT Families Orphans and Children Under Stress (FOCUS) Programme" 1999
23 USAID "Community Mobilization for Orphans in Zambia: An Assessment of the Orphans and Vulnerable Children Program of Project Concern International" 1999
24 Williamson, John. "Finding a Way Forward: Principles and Strategies for Intervention" (draft) 1999
25 Williamson, John. "Children and Families affected by HIV/AIDS- Guidelines for Action" (draft) 1995

- Monitoring vulnerable children and families
- Changing local laws and practices
- Keeping siblings together
- Minimising the need for institutional care
- Addressing psychological issues holistically within the context of children's welfare[26]

Successful strategies that assist children affected by AIDS have focussed on improving the capacity of children, families and communities to cope with the impact of HIV/AIDS.

Children can be assisted to support themselves and siblings through enabling them to stay in their communities and in school, helping them to access training and role-modeling in life and social skills, by reducing the labour demands on their households and by protecting them from exploitation.

Families can be helped to cope better by improving infrastructure, providing access to credit, increasing their ability to generate income, reducing demands on their labour, protecting women's and children's property and other legal rights, ensuring access to health services and responding to psychological needs.

Helping communities to help their own can include respecting and increasing community decision making abilities, enhancing the community's ability to support all vulnerable families, organising skill and labour sharing, and providing training[27].

In summary, those working with orphans and children affected by HIV/AIDS aim to build a world in which:

- healthy and educated children are living at home and in appropriate supportive and protective communities;
- those communities are able to support family-based care for all children and young people, and to provide them with respect and opportunities;
- governments, NGOs and international bodies collaborate effectively at all levels to support community and family efforts to protect and care for all children;
- and leaders in public life believe it is their responsibility and within their power to make life safer for orphans and children living in a world with HIV/AIDS, and to act accordingly.[28]

It is also vital that governments protect the most vulnerable children and provide essential services.

26 *Save the Children. "Promoting psychosocial well-being among children affected by armed conflict and displacement" International Save the Children Alliance Working Group on Children affected by armed conflict and displacement.1996*

27 *Hunter, Susan. Williamson, John. "Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS" Report for USAID 1999*

28 *Francois-Xvaier Bagnoud US Foundation. "AIDS Orphans: Towards an action plan for going to scale" Interagency Meeting on Children Affected by HIV/AIDS. 2000*

4 KHANA APPRAISAL OF CHILDREN AFFECTED BY HIV/AIDS

The formal education system has had to be rebuilt virtually from scratch.

The Khmer Rouge set out to destroy the idea of family, community, education and religion. In doing so, between 1975 and 1979 they created a generation of orphans who lost not only parents, but many members of their immediate and extended families. Subsequent unrest over the next 20 years resulted in difficulties in re-establishing these families and in re-building communities and religious practices. It is, however, precisely these weakened institutions which traditionally have provided a safety net for vulnerable children and orphans in Cambodia.

4.1 Aims and Objectives

It was realised that a definitive piece of work on this subject would take much longer than the time available, but it was felt that issues raised by the appraisal could be flagged for further research at a later date, or investigated by other organisations.

Recognising this fact along with the implications of the growing HIV epidemic, the Khmer HIV/AIDS NGO Alliance (Khana) with the support of USAID through the AIDS Alliance, decided to investigate the situation of children affected by HIV/AIDS in Cambodia. The aim of the appraisal was to gain a qualitative snapshot of the needs and resources of children affected by HIV/AIDS in Cambodia. A secondary aim was to build capacity in appraisal facilitation amongst NGO partners.

Qualitative data from the appraisal, together with existing quantitative data and literature about children and AIDS in Cambodia, is intended to inform further action. An up-to-date bibliography of lessons learned around the world is also included in appendices 3 and 4. Most immediately, this information will feed into Khana planning of technical support to NGO partners on integrating services for children affected by HIV/AIDS into ongoing prevention and care work. It is also hoped that after translation and dissemination, this report will act as a catalyst for other organisations to further consider addressing the needs of children. Finally, it is anticipated that the act of participating in and facilitating the appraisal will in itself make people think about the issues facing poor and vulnerable children.

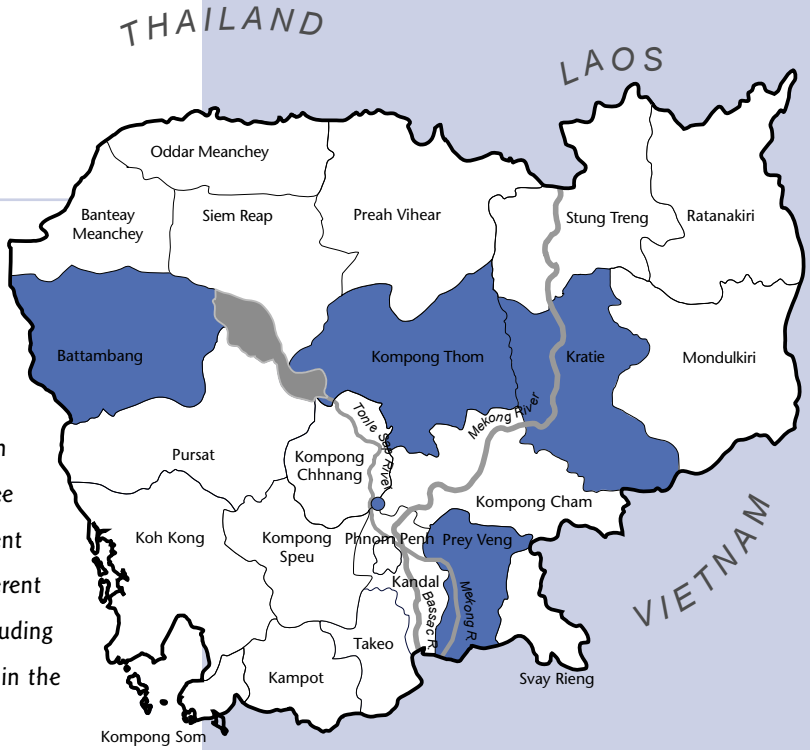
The objectives of the appraisal were to work with a wide range of individuals and organisations to:

1. Determine vulnerability/resilience factors for children
2. Explore how HIV/AIDS-related life events impact on these factors

3. Identify the range of needs specific to children affected by AIDS
4. Identify existing resources which could or do address these needs
5. Identify barriers to addressing these needs
6. Suggest strategies which would begin to fill existing gaps in service provision

4.2 Methods & Limitations

The participatory methods used in the appraisal are detailed in Appendix 1 of this report. The appraisal was facilitated by Khana staff and by staff from 12 partner NGOs. Over 900 people subsequently participated in the appraisal in locations in Battambang, Kratie, Kompong Thom and Prey Veng provinces and Phnom Penh municipality (see Appendix 2b). These provinces were chosen for their different levels of INGO/UN agency activity with children, their different levels of Khana partner activity, their different risk factors including migration and security, and because they are all high priority in the National AIDS strategy.



APPRAISAL PROVINCES

Of the participants, 54% were children including 413 orphans. These orphans were accessed in centres (46%), in villages and communities (34%) and on the street in urban settings (20%). The adults comprised community members and leaders, families affected by AIDS, traditional healers, monks, NGO, UN and government staff. Appendix 2a. details the NGO, UN and government agencies who participated. Forty six percent of participants were women or girls. All participants were happy to participate without remuneration for loss of their time and showed great concern both over the issue of HIV/AIDS and over the situation of children affected by AIDS.

The main limitations noted apart from the short time available were that

- Local NGO appraisal facilitators were sometimes reluctant to ask questions when the participants were government staff in senior positions.
- There was also the issue of potential loss of information through translation. This was compensated for by having 6 analysts (3Khmer and English speakers, and 3 English speakers) working independently

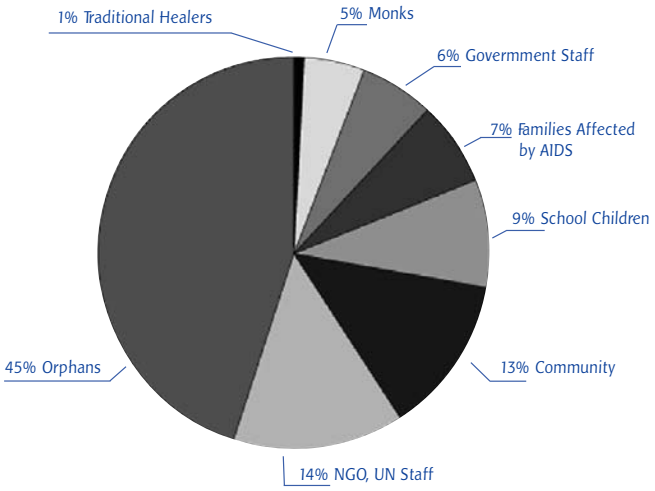
Vulnerability Drawing and Story:

Participants draw picture of 'vulnerable' child and 'non-vulnerable' child of different ages and make up a story about each one. Discussion about comparisons draws out vulnerability and resilience factors. Participants add HIV/AIDS to both stories. Discussion draws out impact of AIDS on vulnerability factors. Participants summarise by defining issues for children affected by AIDS, what helps minimise the impact of AIDS for children and what hinders this process.

with the teams to categorise the findings.

- Of the three tools field-tested (see Appendix 1), the 'Vulnerability drawing and story' and the 'Network diagram of AIDS-related life events' were used much more often than the 'Community support timeline'.
- Discussion with participants did not reveal fully the extent of existing resources. More discussion was focussed on issues, needs and gaps.
- Not all service providers in Cambodia were accessed during the appraisal, and we would be grateful for further information even after this report has been disseminated.
- Although a qualitative appraisal, we were not always able to access anticipated accompanying quantitative data broken down by province.
- The appraisal did not elicit some fundamental issues of best practice. The need to listen to these children, for instance, was only articulated by those working in youth focussed NGOs.

APPRAISAL PARTICIPANTS



APPRAISAL FINDINGS

5

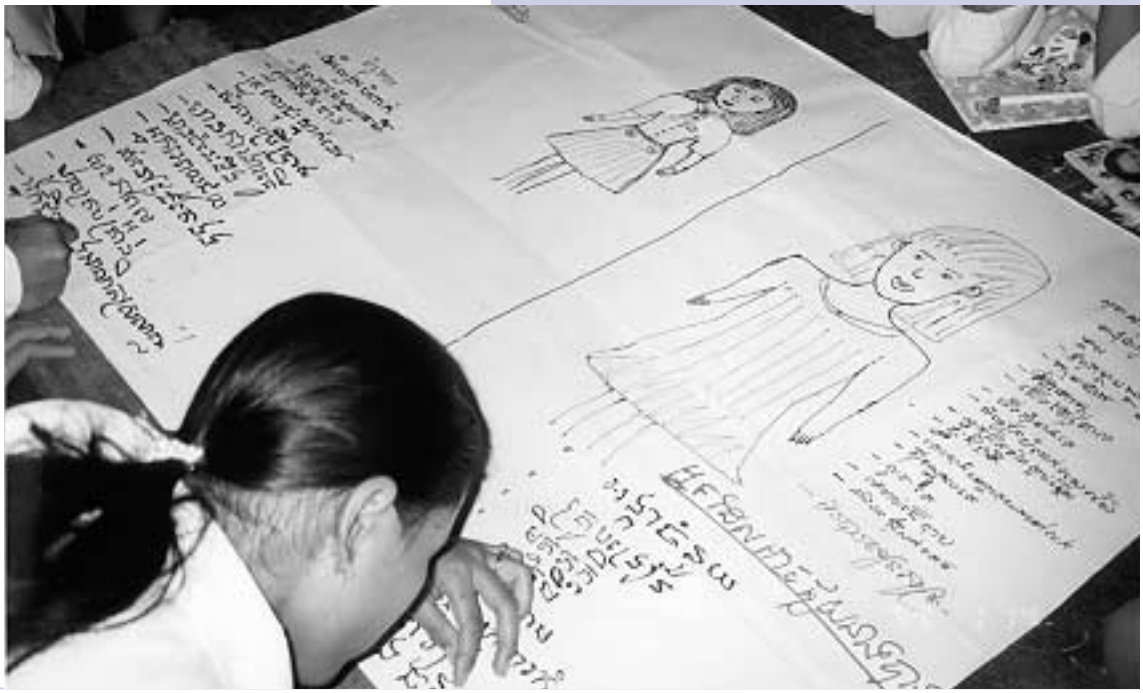
The sheer volume of information generated during this appraisal means that not every example of a particular point is shown in this summary. We have tried to highlight what participants felt were the main issues, resources and gaps for children affected by AIDS. Rather than show these findings in order of magnitude or in discrete categories, they are presented to show how issues link with one another. This linking is in an attempt to ensure that responses for children are holistic and multisectoral and are not just categorised into 'income,' 'education,' 'psycho-social' and so on.

The summary of findings in this report also indicates where there was significant agreement or disagreement between participants, or where for some reason there are gaps in the information.

On the whole, there was a high level of agreement between all participants regardless of who they were. Children, particularly orphans tended to focus more on the details of their lives, but were surprisingly well informed about the bigger picture.

Interestingly, orphaned children disagreed with adults about the usefulness of orphanages and children's centres as a long-term solution for addressing their needs. Overwhelmingly children said they would prefer to live in a family within a community. Violence towards children as a practice and also as a concern was mentioned in many sessions.

No judgement has been made on the quality of the information, but where suggestions for action are contrary to lessons learned in other countries, this has been highlighted. For instance, many participants felt that 'more orphanages' was the main solution to the problems of children affected by AIDS. Lessons learned from other countries clearly indicate that orphanages are not necessarily cost effective, nor in the best interests of the child.



5.1 What makes Children Vulnerable in Cambodia?

Appraisal participants agreed that all children living in poverty are potentially vulnerable since basic needs such as food, shelter, protection, social integration, emotional development and access to health care and education may not always be met. Since over 40% of Cambodians live 'under the poverty line', these general criteria apply to a great number of children. Participants also agreed that this vulnerability can be compounded by a number of factors.

There were numerous examples of these factors which can increase vulnerability including:

- Poor families with many children who have to stretch few resources further.
- Poor families with no relatives or who have migrated away from relatives have fewer opportunities to borrow food or money in crisis situations.
- Parents lacking in skills or education are less likely to be able to find employment on a regular basis.
- Parents who are less able to build up savings or assets which could provide a safety net in times of need.
- Families without land or property who have difficulty in accessing credit with which to start small businesses.
- Families without land can't access basic community development initiatives like rural extension and sanitation projects - which are intended for the most vulnerable.
- Families were stress has resulted in neglect, violence, alcoholism or sexual abuse.
- Families living in areas where there may be conflict or in insecure accom modation such as in squatter areas or on the street.
- Families in which children are required to work either inside or outside the home to ensure survival.

Children's vulnerability is greater when parents are forced to generate income in a way that makes them subject to stigma, police harassment, imprisonment or the payment of fines or bribes. Children of sex workers were reported to be especially vulnerable.

Children in such families were seen to be further disadvantaged where one parent is absent, chronically sick or dead. The exception being where the absent parent was violent or abusive or had squandered family resources for their own ends.

One group of participants quoted a Khmer proverb about it being better for children to lose their father rather than their mother. It loosely translates as "it's better the boat capsizes than the house burn".

Children without mothers were seen to be more vulnerable than those without fathers, since mothers are considered to be generally more concerned about the welfare of their children. Even so, it was clear that participants felt

that women were less able to provide for their children on their own because they lack education, skills, power and status.

Participants also talked about the vulnerability of stepchildren where the step-parent sees the step-child as a threat to their own children's welfare.

Girls were seen to be more vulnerable generally than boys since they are more likely to be trafficked, raped, or sold to brothels. Girls were seen to have less freedom than boys, have less education and generally less control over their lives. They were also seen to be culturally more passive and therefore less likely to be able to stand up for themselves.

The most vulnerable children overall, however, were seen to be those from poor families who had lost both parents.

The most vulnerable age group was seen as 7 to 12 years for both boys and girls. This age group was considered to no longer attract the protection afforded to babies and infants, to be old enough to work, but to lack life skills and the physical strength to protect themselves. They were also seen as the age group most likely to suffer from malnutrition and associated ill-health.

5.2 How does HIV/AIDS Affect Children's Vulnerability?

It seems that most often in Cambodia, male parents become infected with HIV first, then infect their wives or partners. Government and NGO appraisal participants providing care and support to people with HIV said that in a typical situation, the father will fall ill first and die after a series of progressively worsening illness. Very often the illness and subsequent death is not known to be related to AIDS and the mother will only find out that she is infected if she becomes pregnant and the baby then dies. Some time after, she too will become ill and die, leaving the remaining children as orphans.

In order, therefore, to tease out how HIV/AIDS impacts on the factors which make children vulnerable in Cambodia, appraisal facilitators asked participants to look in more detail at 3 different scenarios:

1. Children with parents who are sick with HIV related illness
2. Children whose parents have died of AIDS
3. Children who are themselves infected with HIV

Most participants had some experience of the first 2 categories, some more directly than others, but only a few were able to offer information about the needs of children living with HIV.

Common Clinical Problems encountered by PLWHA in Cambodia include:

- *Diarrhoea*
- *Fever*
- *Pain*
- *Chronic cough*
- *Skin lesions*
- *Oral Thrush*
- *TB*
- *Herpes*
- *Oesophageal Thrush*
- *Pneumonia*
- *Cryptococcal Meningitis*

Sophy moved with her husband Duong and their children from their home province in Kratie to Pailin so that they could work as gem miners. This proved to be a profitable move and after some time they were able to buy a house and a small piece of land for growing crops. They also had a fourth child - a son after 3 daughters. Just when they thought they were doing well, Duong became very ill. Sophy kept thinking he would recover if only they could find the right treatment. She sold the land to pay for treatment, but Duong did not get better. Sophy tried hard to continue with a normal life for her children during Duong's illness, but found it very difficult. She just did not have time to care for Duong, make money to buy food and give the children the attention they needed. She couldn't find people who could help her without payment, and she couldn't afford to pay. All their relatives, friends and neighbours were far away in Kratie. Eventually Duong died. Sophy had begun to hear about AIDS by this time, and suspected that Duong had been infected with HIV. Every time she thought about this, she felt like a criminal. She was so ashamed that she could not talk to anyone about it and hid the details of Duong's illness from his family. Not long after this, Sophy herself fell ill. Her eldest daughter, Nara who was 12, had to take on the burden of the household. Now Nara had to look after her 3 siblings, including a small baby, care for her mother and find money for food. Every day Nara worked with the gem miners to dig holes 5 meters deep to find gems. Sometimes she was lucky, but most times her efforts were in vain. Nara worried about her Mother. It had been terrible to lose her Father, and Nara did not like to think what would

5.2.1 Issues for Children Whose Parents are Sick with HIV

Appraisal participants reported that when the father or male head of the household becomes sick, there is a chain of events which impacts on the children. After some analysis, the majority of participants said that adding HIV/AIDS to the lives of already vulnerable children makes them more vulnerable. They said that this is because there are many negative impacts generally occurring within a relatively short space of time; because the psychosocial impact is high and because if HIV/AIDS is actually known or even just suspected, there can also be a high level of stigma.

Increasing Poverty

Because the signs and symptoms of HIV-related illnesses are not commonly recognised as being such, treatment is sought and the family spend progressively more time and money trying to find a cure. HIV Counselling and testing facilities are not widespread, so people often do not know their status and are not able to plan resources appropriately. This means there are less resources for the children and often one or more, usually girls, drops out of school either to care for the sick parent or because there is no money for school fees. Eventually land and property, including tools for income generating (sewing machine etc) may also be sold to pay for treatment. The father may lose his job through being off work too often. More money is spent on transport to health centres or for hospital stays. Children may have to work to generate income for food, or look after other siblings to free up the mother's time. Often credit is sought in the hope that the parent will eventually recover and be able to pay off the loan. Because this does not happen, the family can slide into debt. If the debt is for instance rice, loaned by neighbours, the family can lose local support and the chance of further loans. If the debt is to a money lender, the family risks harassment and violence. It was reported that children are often expected to pay back loans even after their parents have died.

With the loss of labour and money spent on treatment, the family can quickly slide from a relatively secure position into increasing poverty, vulnerability and ill health.

Family Stress

During this time of parental sickness, participants reported that the added stress and uncertainty can often result in fighting between husband and wife and a general increase in domestic violence. It was reported that men are more likely to become violent under stress, and that women are more likely to become withdrawn. Where there is a suspicion that the husband has HIV, there can also be a great deal of blame and guilt involved. Neighbours, relations and in-laws may take sides or may isolate the family completely. Although against government policy, health workers sometimes test for HIV without permission and have been reported to disclose an HIV status to relatives without telling the patient. The family turmoil created through these events can result in complete breakdown with divorce or separation of the parents and a further change in circumstance for the children.

Children's Isolation

Children suffer in this situation in ways that are not always evident. Often, parents who are feeling sad and guilty or who are preparing for death, will keep children at arms length, or send them away, in order to be able to cope with their own feelings. Sometimes children are sent to live with relatives or to work as servants in other houses. This means that these children lose any emotional and physical support networks that have been built up through friends and with other adults in their community or through school. They lose their 'normal' status and can become depressed through seeing themselves as different to their peers. It was reported that some children would prefer not to go to school rather than lose face by people knowing they cannot afford fees. Children also suffer greatly through watching a parent die, or through caring for a parent who is in chronic pain. Often there is 'shame' attached to the illness and they are not able to talk freely about their fears and anxieties. Neighbouring children may not be allowed to play with them for fear of infection, thus further increasing their sense of isolation and of being different. Older children have to take on adult roles without skills or knowledge, often they are exploited or cheated. It was reported that on the whole, adults don't usually relate to children as 'people' with minds of their own and don't bother with explanations if the child is under 11 years of age. The stress of not knowing and not being able to ask, can be intolerable for children. Some run away and become open to further abuse, violence and poverty.

happen to her if she lost both parents. When the baby also became sick, everything became too much for Nara. Sophy sent a letter to her sister, who came at once. They sold the house and remaining possessions to pay for travel, and returned to Sophy's sister's house in Kratie. Only 5 days after they arrived, Sophy died. Several weeks later, the baby also died. Sophy's sister is herself a war widow with three children. She has continued to care for Nara and her two sisters after Sophy's death a few months ago, but has found this difficult since she has no skills which would help her find a job, nor capital to start a business. The community have been good to the family. They know that Sophy and Duong died of AIDS, but they have not isolated them. They would like to give more support to Nara and her sisters, but they themselves have few resources. None of the 6 children in the household have been going to school, but they would very much like to be able to.

Shortly after Sophy died, a couple from outside the community who live across the river offered to adopt Nara's 9 year old sister Rie. The Aunt signed a contract saying that Rie's relatives cannot claim her back once she has gone to live with the adoptive couple. Now she is worried she has made a terrible mistake. Rie misses her sisters and they hear that she wants to come back. They do not know if she is being well treated or not. Nara helps her Aunt as best she can, but she appears listless and depressed and cannot concentrate on her tasks. Her Aunt thinks it will take Nara a long time to come to terms with what has happened and worries about her future.

Lack of Support

Where there is little knowledge about HIV, neighbours and relatives will not often offer to help care for the sick parent. It was reported that this type of discrimination is usually through fear of transmission or through superstition at what will happen if they associate with someone they consider to have done something bad. Most often, there is little support purely because people are too poor to offer much. One group of participants reported that people with HIV are feared because they know they will die and therefore can "do anything they want, even murder". In some areas participants said that health staff refuse to treat people they suspect of having HIV infection because they do not have the skills and are scared of infection. Similarly, only a few monks were reported to offer spiritual help to people known to have HIV, but this number is growing thanks to targeted NGO work with pagodas. In the few places where there are Home Based Care Teams the situation is much better for the families. Participants said that seeing other people caring for their family helps relatives to lose their fear and in some cases shames them into helping

Women Coping on their Own

When the husband dies, the situation is compounded. There is a funeral to pay for, and the stigma to be faced when few people attend, although if monks have been visiting and providing counselling to the family, they may contact the Pagoda to assist with the funeral. If there is property remaining then there can very often be conflict about who should inherit. Often by this time the mother suspects she also is infected and has to face the prospect of her own death and of an uncertain future for her remaining children. It was reported that this can lead women to feel such despair and hopelessness that they consider abandoning their children and sometimes actually do abandon them. Government health workers reported that sometimes women leave their babies in the hospital in the hope that someone will look after them. This can also be the time when families become homeless. Brothel owners were reported to chase out female sex workers and their children if they suspected the woman to have HIV. Families in government sponsored housing (families of uniformed personnel) may also have to vacate on the death of the husband, although it was reported that families of policemen were given welfare by their colleagues.

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Sombat is 17 years old and lives in Phnom Penh with his five brothers and sisters. Sombat is the third born in the family, he is pale and suffers from anaemia. Three years ago his father died of AIDS, then in 1998 his mother also died. Sombat remembers when his father became ill and how his mother blamed his father for bringing HIV into the family. His parents fought a great deal about this and the household was very stressed. After his mother died, Sombat's elder brother developed chronic depression, and died in an accident. Sombat and the remaining children have a house which was left to them by their parents, but have little furniture and few household materials. They do not have enough food to eat even though one of the girls also dropped out of school to get a job selling newspapers. The younger children are able to continue school, but do not go regularly. At the weekends all children including the youngest who is 5 years old, go out to try and find small jobs they can do to earn food or money. Sombat says their neighbours never come to visit, but that they do have an aunt they can go to for food every now and again. Other children in their neighbourhood refuse to play with the younger brother who is aged 9 years. He doesn't mind because he has friends at school who don't know the family situation.

It was reported that land rights vary enormously and that laws are currently being prepared on the legal status of land property. There is a tradition of family inheritance, but often disputes arise where 'uncles' arrive to claim land from orphans. It was reported that the military often take land from vulnerable families.

Grandparents

Grandparents were the favoured option of the majority of participants since they were seen to have close blood ties to the orphaned children and would therefore be motivated to care for them. It was also felt that living with grandparents would result in children not being looked down on by the neighbours. Unfortunately in Cambodia, there are relatively few grandparents. Only 4% of the population is over 60 years compared to 10% in Singapore[29]. Quite often, those adults dying of AIDS were themselves adopted by these 'grandparents' after their own parents died during the Khmer Rouge era. Grandparents also have concerns and difficulties of their own. Most will have given up work and will themselves be dependent on their extended family. Some are ill and infirm and find it a problem to have to start work again. Because of their age, they are usually denied credit, which makes it difficult for them to start small businesses. Very often, an older orphan will have to generate income for the grandparent and other siblings. Even despite this, grandparents as carers were seen to better provide for orphans socially, psychologically and physically than anyone else. The terms 'love' and 'parental affection' were ones used most in conjunction with grandparents, who were considered able and willing to nurture children in a way their natural parents might have done. This concept of nurturing was not associated with other options for orphans.

Other Relatives

Children sent to live with other relatives after the death of their parents were said to enjoy a mixed fate very dependent on the good, or not so good, intentions and nature of the relative in question. Participants were suspicious of the motives of a poor relative who would take on the care of an additional child or more rarely, children. They felt that often the child would be seen as an investment, either for labour in the relatives home, if a girl, or for income

29 HelpAge International. "Summary Report on The Situation of Older People in Cambodia" 1998 Report with the Cambodian Ministry of Social Affairs, Labour and Veterans Affairs

generating or agricultural work outside the home if a boy. They felt that there was also a possibility of them taking a child to eventually sell to a brothel or as a bonded worker elsewhere. Many participants felt that orphansare treated as having a lower status than other children in the family,are expected to do more work, get less food, are not able to attend school and are subject to moreviolence. Where relatives take on the care of orphans because they feel it is expected of them, participants felt that there would be resentment which would result in abuse. It was felt that relatives are much less likely to offer to care for an orphan where one or both parents are known to have died of AIDS. Orphans themselves, felt they had to be extra nice to other relatives who took them in, just in case they got angry and abandoned them completely. They complained of a lack of freedom and of not having the time or opportunity for play and entertainment. Those other relatives caring for orphans who participated in the appraisal on the other hand, were worried that the children would not return their care as they got older. They felt that the orphans in their care were not likely to feel any obligation to look after them in their old age and were worried how they would cope.

"I work hard to make others love me"

"I want not to have to beg"

"I want to make friends and eat sweets"

"I want a school bag so that I can look like other children"

"I want the same rights and freedom that other people have"

Orphans Group

Adoption

Sometimes, childless relatives or non-relatives will formally adopt an orphan and bring them up as their own child - although this practice was reported to be unregulated with no vetting procedures or monitoring. This was a situation that often came up as an ideal for orphans in the appraisal. This scenario, although relatively rare, would mean that the child could see him/herself as being like other children and have a chance to develop through childhood into skilled adults. This type of formal adoption, however, was felt to apply to single children only and that there was little likelihood of childless relatives adopting a number of brothers and sisters together. At other times children can be adopted by way of contract by people outside the family. Again, participants were suspicious of any poor person taking on an extra burden without an ulterior motive.

There were stories during the appraisal about outsiders selling girls to brothels or trafficking them to Thailand.

Monks

There are now over 3,000 Pagodas throughout Cambodia. Monks traditionally take in orphans, mainly boys but also girls over 7 years either to participate in religious life, or as workers in the Pagoda. Children usually need a formal introduction for this to happen, either by parents before they die, or by a respectable relative. Pagodas can only support a small number of orphans since they are totally reliant on offerings from the surrounding community. Those they do take in, however, are clothed, fed and educated and have the prospect of a relatively good future.

Monks also provide food and shelter to other children in need, but do not commit to their education or socialisation. On certain days, any left over food in the pagoda was reported to be given to people in need, particularly children. In two participating pagodas, however, there was a great deal of tension between the monks and nuns and what they described as gangs of children who took food before they were offered.

Orphanages and Children's Centres

There are reported to be 21 children's centres in Phnom Penh, which care for 1798 (695 girls, 1103 boys) orphans in total. Thirty nine of these orphans were reported to have HIV.

There is a government orphanage in most provinces, and several NGO Children's Centres around the country. Most adults felt that institutions were the best solution for orphans, but the children themselves disagreed. Those orphanages visited as part of the appraisal were providing basic food and necessities and sometimes a level of education to the children, but the children had other priority needs they felt were not being met. Mostly they felt that a sense of belonging (to a family or community) was missing, and they hated being 'different' to other children. One orphan said that 'even children who live on the street look down on us because they have parents and we do not'. Despite this, adults continue to send children to orphanages, so much so, that the applications far outweigh the places available.

Emotional Impact

Very often, siblings are split up to spread the resources, and children have to move from the area or community they call home. In cases where the parents have migrated for work, they have never met their extended family and may encounter a way of life that is entirely new. They may be separated from all people familiar to them and become depressed as a result. Being separated from brothers and sisters was reported to be as traumatic as losing parents, since siblings can be a tremendous solace and source of support.

Orphans may also be suffering from the effects of grief and stress. Those whose parents have died of AIDS may also worry that they themselves are infected, or may have a sibling who is sick from HIV who may soon die. They can also feel that they have in some way caused their parents death and suffer from guilt. They may be very tired and in ill health from caring for a dying parent and from trying to look after their siblings. It was reported that all these stresses, plus ill treatment from relatives sometimes forces children, mainly boys, to run away to the towns. This places them on urban streets and potentially in even greater danger.

Participants reported that children newly orphaned may appear to be badly behaved because they have difficulty concentrating, get angry easily and appear sad and anxious. They may be punished for this behaviour.

Children on the Street

There was some confusion about the term 'street children'. In Cambodia, the majority of children seen living on the street are living there with their parents. Children on their own sometimes live in gangs. They may have parents elsewhere, or may be orphaned. Girls were seen most often to end up in sex work and to be highly vulnerable to rape on the street. According to the adults in the appraisal, these gangs have a bad reputation for petty theft, bad behaviour and glue sniffing. Adults reported that street orphans are pale, thin and dirty and that they are not attractive to people who may otherwise be motivated to help them. Orphans who took part in the appraisal complained of malnutrition, ill health and having nowhere to wash. They were also very worried about being terrorised by gangs - teased, beaten and of having food and money stolen. Conversely, children also reported taking care of one another in gangs on the street by showing who would be good to beg from and by massaging each other when they got sick. Gangs were seen as a form of solidarity against adults who exploit children living on the street. These children said they had nothing at all - no house-

Survival strategies for orphans living on the street were reported to include selling sex, begging, helping street vendors, picking through rubbish for something to sell or eat, and taking food from restaurants that customers have not eaten.

hold utensils, mosquito net nor bedding. Often they had to resort to theft and other forms of crime. They felt they had no chance to participate in society. Sometimes they fall foul of the police who may beat them or send them to reform school. Very occasionally it was reported that police would offer protection.

5.2.3 Issues for Children with HIV

Participants from the community generally had little knowledge about the situation of children with HIV, so most of the responses in this section came from NGO and government staff working directly with these children. Participants reported that children with HIV are less likely to go to relatives and more often go to orphanages or live on the street. They felt that relatives are more likely to accept and love children if they understand well about HIV and know the true situation. Some participants felt that children with HIV were less likely to be loved or benefit from investment in education because they will die soon. Others felt that reverse to be true, but that sometimes poor people find it difficult to cope emotionally with a child who is sick and in pain and wish they would die soon to end their suffering. It was reported that sometimes children with suspected or confirmed HIV/AIDS are not adequately diagnosed or treated due to the mistaken belief that it is a waste of time as they will die anyway.

Participants said that in their experience, a child infected by his mother has at least a 60% chance of surviving more than one year in Cambodia, and that with good prevention and care, they may live much longer than this.

Hospital workers said that there is a problem of follow up for children with HIV, that carers need training and support so that relatives don't just leave the child in hospital.

HIV positive children usually have the same illnesses as children without HIV, but they may be more severe, frequent and difficult to treat. It was seen as very important that carers follow both preventive measures and early treatment of symptoms. Routine immunisation was seen as particularly important for children with HIV, with the exception of BCG (TB) vaccination if the child is already in advanced stages of AIDS. Good nutrition and basic hygiene were seen as vital. As with HIV positive adults, a balanced diet of nutritious foods is very important to maintain the immune system.

Sothiny's father died when she was a baby. From the time of birth, Sothiny had suffered from persistent diarrhoea and skin infections. At the age of 3, after a particularly serious episode her Mother took her to hospital. They tested Sothiny's blood without permission and told her Mother Sothiny would die of AIDS. Sothiny's Mother did not understand then when they explained about HIV . Now 2 years on Sothiny is still alive and her Mother is starting to hear people talk about HIV. She realises this is what Sothiny has and is worried about herself and her other children. Sothiny has remained

Despite the risk of infection through breastmilk, it is recommended in Cambodia that all babies are breastfed for at least 4 months, as the risk of illness through alternative feeding practices is much greater. Many poor families cannot in any case afford formula milk. Like all children, participants said that children with HIV should go to school, play with friends and feel loved by their family.

Despite there being no risk of infection to other children through normal social interactions, children with HIV suffer particularly from the fear surrounding transmission of the virus. Parents and teachers, worried that other children may be at risk, do not allow them to play or mix in a normal way. Participants reported that this can have a strongly negative psychological effect on the child who is isolated.

Some of the more serious illnesses that children with HIV may have, such as PCP, toxoplasmosis and cryptococcal meningitis are extremely difficult to diagnose and treat in Cambodia. Participants reported that hospitals may only be able to offer pain relief, but that it is important to make sure that parents and carers are clear about the likely progression of their child's condition in order to begin to plan ahead.

Policies on the prevention of mother to child transmission of HIV are currently being developed in Cambodia. However, the National Centre for HIV/AIDS, Dermatology and STD (NCHADS) has stated that it is not one of the main priorities in the current Cambodian context. HIV testing and subsequent treatment of pregnant women has begun on a small scale in selected hospitals in Phnom Penh, but is unlikely to become widely available in the foreseeable future.

more sickly than other children causing her Mother to have to stay off work and use limited resources on drugs. Even though she is a happy child, other children don't always want to play with Sothiny because she is often coughing and has unsightly rashes. The mother can't forget that she was told that the child would die and wonders whether to bother paying school fees if this is the case.

5.3 Resources for addressing the Needs of Children Affected by AIDS

Specific needs were identified during discussions with participants. Some needs could potentially be met with existing resources, and those mentioned by participants are detailed below. Where relevant, barriers to these resources being accessed are also detailed in the text. Specific details of NGO, UN agency and government resources for HIV/AIDS prevention and care can be found in the regularly updated UNAIDS Country Profile. Details of the activities of other NGOs can be found through CCC and also through MEDICAM.

The Resources of Children

Brothers and sisters were seen to be a powerful support for one another, except where the pressure for resources and food becomes so great that they eventually need to compete with one another. Participants said that siblings can and do care for one another, teach each other skills and look out for each other's interests.

The Resources of the Families

As already mentioned, mothers are generally concerned for their children, but women headed households, especially where the woman is sick, were shown to be greatly disadvantaged. Grandparents were shown to be willing to provide good quality care for orphans, but that often they lacked the means to do so.

Grandparents and other relatives were seen to be important both to support a family where parents are sick, and also to care for children orphaned by AIDS. They are seen to be important in the social education of children, as parental role models and to provide information about a range of life skills. Sometimes the extended family are not able to help because they themselves are too poor or because they are afraid of infection or being associated with bad karma. Sometimes extended families are far away, or have themselves died.

The Resources in Communities

The usual community support systems of neighbours, community leaders, community associations, the Pagoda, traditional healers and teachers were all seen to be important resources for children affected by AIDS and their parents. Again, fear of infection was seen to be a barrier, as was poverty in most communities.

A small number of community associations were reported for self-help for funeral costs. Monks were seen to have potential for ongoing emotional support for the whole family, but they were considered to need some training in HIV/AIDS specific issues. Friends and neighbours can provide practical support in household tasks, house repairs and caring for small children. With some training they can also provide respite care for those who are sick or dying. Friends and neighbours can also check on newly orphaned children and provide household materials, clothes and food.

Community and religious leaders were seen to be able to persuade head teachers to reduce school fees, although other parents would then have to contribute more. Teachers can allow poor students to economise on materials (for example to use one book for all subjects), although any concessions at school need to be implemented sensitively to maintain confidentiality and reduce discrimination. Community leaders can and do mediate in domestic conflicts when families are under stress. They could also protect the land and property inheritance rights of widows and children, but sometimes even they were not considered powerful enough to do this.

Community members in general were also seen to be important for providing social opportunities and friendship to children affected by AIDS to prohibit isolation, alleviate stress and promote their development into adulthood. Traditional healers were said to provide treatment for opportunistic

infections and psychological support to families. With some incentive they could also monitor the health of children in families where parents are sick and the health of orphans.

Resources Provided by People Living with HIV/AIDS

There are still few formal support groups for people living with HIV/AIDS or for people affected by AIDS in Cambodia, although indications are that such groups are on the increase. Some participants talked about informal self-help activities whereby children will be cared for by another family affected by AIDS when one or both of their parents die. Although this was seen as extremely positive, it was recognised that these families themselves live in poverty and under stress with little support, and that there is a danger of further ostracisation. Children would also be liable to losing a series of substitute parents.

Resources Provided by Businesses

Very few participants mentioned business people as resources. Some said local businesses could be encouraged to take on vulnerable children as apprentices, or to offer other job and training opportunities. Others said they could be made aware of the situation of children affected by AIDS and asked to contribute food, materials, drugs and money through communities or NGOs.

Resources Provided by NGOs

International and local NGOs were mentioned most often by participants as existing resources for children affected by AIDS. Many local NGOs described themselves as small-scale holistic community developers providing a range of services to their communities. For example, the same NGO may have projects in irrigation, credit, and reproductive health with 10 villages in the area. Most NGOs are also located in urban centres of Cambodia, which leaves the majority of the population in rural areas underserved. Many participants in the provinces remarked that there were few NGOs in their area. In addition, participants felt that many local NGOs were in need of technical and organisational support, particularly when they have no existing links with HIV/AIDS work. A small number of NGOs provide capacity building services of this kind to local NGOs, including Khana itself.

In addition to those NGOs who specifically work on HIV/AIDS and who can be accessed through the HIV/AIDS Co-ordinating Committee (HACC), there are other NGOs who work with families and children. Some NGOs provide counselling, although these are few and far between and there is little expertise in AIDS counselling or counselling for children. In Cambodia only one local NGO is known to be dedicated solely to HIV/AIDS work in the provinces, there is currently only one independent support group for people with HIV, and there are no NGOs focussing solely on children affected by AIDS. NGOs are also helping to provide access to credit in poor communities, it is difficult for them to extend credit without collateral which means that the poorest and most vulnerable (also the very old and the young), are often excluded. Other NGOs focus on agriculture and rural development, but families often need to be landowners to take advantage of these programmes.

Some NGOs help children to access education and primary health care. Others teach a range of life-skills to young people (hygiene, sexual health, family planning, relationships, decision making etc). A few work in the field of children's rights - both practical implementation and community-based training. There are some projects aimed at preventing trafficking, or at rescuing children who have been trafficked. Some NGOs work to reduce the incidence of domestic violence and to raise the status of women in Cambodia.

Some NGOs focus exclusively on widows or female headed households. Others work directly with sex workers or the families of migrant laborers. A few NGOs work directly with street children, offering a range of services and training. Drug use is the focus of a very few. Other NGOs provide complete care for orphans in centres and in children's homes. Many of these also work to integrate orphaned children back into communities or with extended families. Some NGOs are medicalised and provide free or cheap treatment to poor families. One organisation mentioned in the appraisal organises overseas 'foster parents' who donate money and toys to orphaned children. Another INGO has a formal foster care programme which regularly monitors the status of the children.

Government Resources

Government resources mentioned in the appraisal included HIV counselling and testing facilities which are provided by the government but limited to 5 provinces and only in the provincial town. Also mentioned was the training of government health workers in HIV, but participants reported that many still do not know about the needs of people with HIV even if they are tested, and that this especially applies to childr
en.

National Guidelines have been drawn up on a range of HIV/AIDS related issues including on the management of paediatric AIDS, although appraisal participants felt it was not clear when or how these guidelines will be disseminated and staff in the provinces trained.

Participants said that some Phnom Penh hospitals have the capacity to treat the more severe AIDS-related infections and that home care staff from 10 health centres in Phnom Penh and 2 in Battambang have some experience in supporting children with HIV and their families. It was also reported that there are government plans to scale up home-based care in the provinces, but as yet no funding is secured for this.

With regard to education, participants reported that research on the situation with regard to the education of children with HIV and their status within the school system has been planned. Also that in some areas HIV is already integrated into school curriculums. This is in order to provide knowledge about prevention, but also to dispel fear and discrimination.

On-going training in HIV for field workers from the Ministry of Social Affairs was also reported. Participants in the community mentioned the potential for extension workers particularly from the Ministry of Women's affairs and from the Ministry of Rural Development to support children affected by AIDS.

Local authorities were mentioned most often by street children. Some had been allowed to squat in an illegal area, or had been helped in some way by the police. Most often, however, participants felt that local authorities did not prioritise the situation of vulnerable children let alone those affected by AIDS. They also felt that street children were beginning to be seen as a nuisance, rather than as children in need of assistance, and that the police were inclined to harass rather than to help children.

5.4 Gaps in Meeting Needs

Despite being able to describe a number of existing resources, a significant number of gaps in addressing the needs of children affected by AIDS were identified by participants. Many suggestions as to how these gaps could be addressed were also given and are summarised below.

Widescale Prevention Education and Skills Training

1. Most participants pointed to the need for widescale prevention education and skills training at community level. Not only should this result in less people contracting HIV infection, but they felt that this would result in less fear, and potentially more offers of help when someone is sick. They felt that a better understanding of HIV transmission would mean more offers of care for AIDS orphans, and possibly a better standard of care from relatives and friends.

2. Participants felt that community leaders, monks and particularly teachers should be targeted for HIV/AIDS education since they are in a good position to influence both behaviour change for prevention and positive attitudes for care.

Mainstreaming HIV/AIDS Prevention and Care

3 The need to mainstream HIV/AIDS prevention and care with all NGO and government activity at community level was also highlighted. This would mean integrating HIV/AIDS work with for example, credit and savings activities, water, sanitation, agriculture and community health programmes.

Role Modeling Prevention and Care

4 Participants said there was a need for more on HIV/AIDS on the radio and television, but that role modeling contact and care for people with HIV in the community was the most important strategy.

5 Similarly, it was felt that influential people in the country and in the communities should promote a more positive attitude towards people with HIV/AIDS.

HIV Counselling and Testing - Pre, Post Test and Ongoing

6 Participants also overwhelmingly pointed to the need for access to specialised HIV counselling and testing so that parents with HIV would know not to waste resources on inappropriate treatment and could be helped to plan for their children's futur

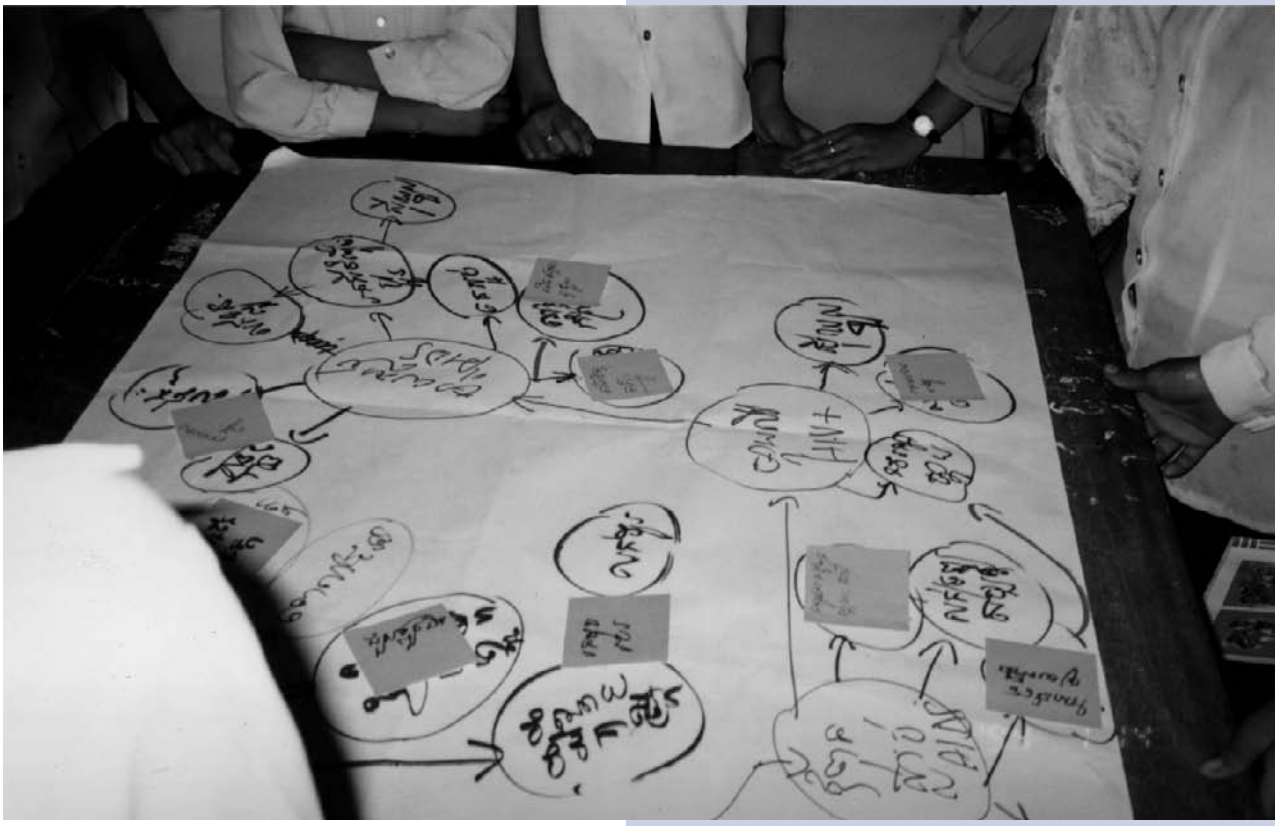
7 This planning was seen to be part of on-going HIV counselling which would also serve to reduce family stress and isolation.

8 Children could also receive counselling, which would help to reduce guilt and anxiety and enable them to grieve.

9 Some participants felt that it was important for all couples to be able to access counselling and testing before marriage and before having children.

10 Counselling a terminally ill child and their parents or carers is a special skill. Specialist training is needed in this type of counselling, and very few people in Cambodia have yet had experience of counselling in this situation.

11 Preventing transmission from mother to child should be promoted, but drug treatment should only be available as part of a wider care package for families. In particular, greater availability of counselling and testing would allow couples affected by AIDS to make informed decisions about having children.



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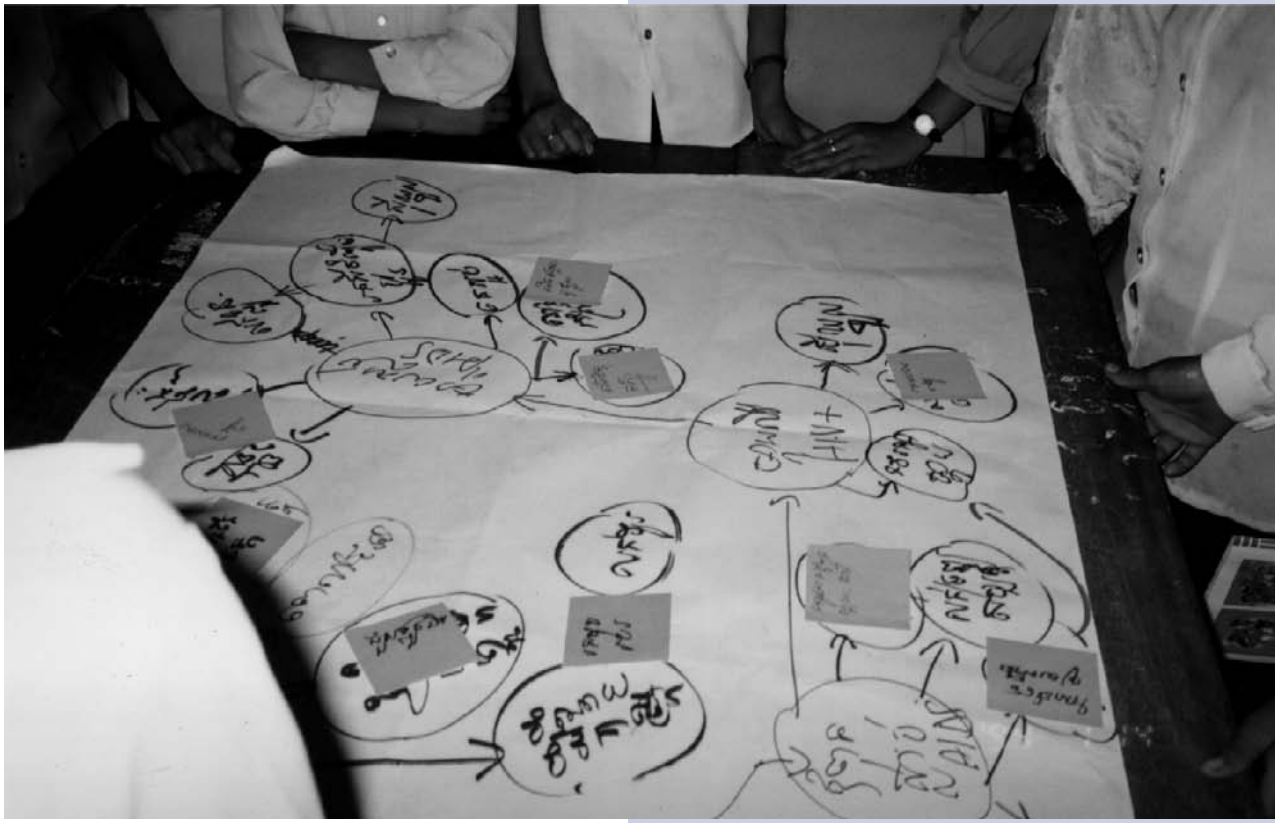


Advocacy

20 Participants felt that a strong NGO specialising in the needs of children affected by AIDS would help in advocacy, and persuade others - including relatively wealthy business people - to provide direct and indirect services which may assist these children.

Government and Legal Reform

21 To generally reduce the vulnerability of families affected by AIDS, participants urged faster reforms in government health care, better access to specific drugs and better transport/roads to health centres, schools and hospitals in rural areas.

22 They also wanted to hasten widespread training of government health (and other sector) workers on HIV/AIDS.

23 Participants suggested that government social workers and child caseworkers should be trained and that provincial strategies for child protection should be drafted and most importantly, implemented.

24 Participants wanted government to clamp down on fraudulent inheritance claims and draft clear laws for land ownership.

25 Participants wanted legal protection implemented for children with regard to labour exploitation, sexual abuse and trafficking.

26 Some felt that vulnerable children should be enumerated and targeted for protection by local authorities and that all orphans should be given free education subsidised by the government.

27 Education for the police on child protection was seen as a priority.

28 It was also suggested that orphanages should be improved and that they should only take the most vulnerable children.

Community Mobilisation

29 Some suggested that communities form committees which hold land in trust for orphaned children until they reach majority.

30 Some also mentioned replicating community savings schemes by involving community members in assessing schemes that work.

31 They also suggested supporting Village Development Committees (which are widespread) to look after the interests of vulnerable children and those affected by AIDS and to mobilise the community to do the same.

32 Some participants mentioned that the role of traditional healers could be enhanced by forming local networks and providing training. These healers could then be formally linked with providers of home-based care.

Economic Strengthening of Children and Carers

33 Participants felt that NGOs could provide start up materials and training for small businesses to people with HIV, widows, grandparents caring for orphans or to children affected by AIDS themselves.

34 Others felt that vocational training was a waste of time unless the economy was significantly improved so that there were markets for these children's and their carer's skills.

35 Many participants mentioned that low interest loans should be targeted without security at people with HIV, widows, grandparents caring for orphans or to children affected by AIDS themselves.

36 Others felt that savings schemes could be more effective if communities started these before they began to feel the impact of AIDS.

37 Participants also suggested direct support to grandparents or relatives who take on the care of a child orphaned by AIDS. Suggestions included business people or those relatively well-off to 'adopting' a grandparent; food aid being given to families by NGOs; school fees being subsidised by government or by INGOs; food for work programmes; donations of

household materials and school books; providing free medical care to vulnerable children and their carers.

38 Some preferred to see carers of all vulnerable children supported - not just those affected by AIDS.

39 A few participants suggested supporting orphaned children to stay in their own homes and communities and help them to look after themselves.

Drugs for Opportunistic Infections

40 Participants mentioned significant gaps in addressing the needs of children with HIV. The drugs needed to treat complications associated with late stage paediatric AIDS are not available in Cambodia, or only at great expense. In addition most hospitals do not have the capacity to accurately diagnose these conditions.

Skills for NGOs

41 It was suggested that NGOs be assisted to build skills in working with children in distress and to research strategies for promoting the psychological and emotional welfare of children.

42 Further, it was suggested that the NGO sector generally be strengthened in terms of organisation and technical capacity, both to access available funding and also to integrate appropriate services for children affected by AIDS into on-going HIV/AIDS work.

6 CONCLUSION

The process of appraising the needs and resources for children affected by AIDS in Cambodia has been a positive one for Khana. For the first time staff from NGO partners facilitated on equal terms, more than demonstrating their increased capacity for participatory appraisal and for using tools and techniques in a sensitive fashion. Also positive was the active participation and evident concern, for children affected by AIDS shown by adults from all walks of life. The methods used allowed information to be triangulated, and there were some very interesting findings. Although only a small portion of the review of existing literature is mentioned in this report, Khana has been able to learn a lot about good practice and appropriate responses in other countries through this exercise.

It is recognised, however, that this appraisal represents only the first in many stages of planning and implementing a response to the issues, and that there are still many significant gaps in both the breadth and depth of the information shared with Khana. Examples include that:

- The appraisal fails to show the scale of the challenge and where the greatest need is. Quantitative data on children affected by AIDS, orphaned and vulnerable children generally, particularly by Province, is needed to appreciate scale and location.
- Although the appraisal points the way, there is a need for more systematic investigation about existing resources and potential resources at national, provincial and most importantly at individual community level.
- Further knowledge is needed about projects and interventions that have been effective in other countries and why they have been effective.
- We need to know how acceptable imported solutions may be within the context of contemporary Cambodian culture and society.
- A great deal more needs to be understood about the psychosocial impact of AIDS on children in Cambodia - how to recognise distress and how best to help a child to cope.
- Further information is also needed about strategies to promote children's natural resilience.

Given the relative lack of information about the psychosocial impact of AIDS on children in the appraisal, Khana has chosen to give this issue first priority. Directly following the appraisal, 2 workshops were conducted for 26 NGO partners and members of their communities for a total of 80 participants from all over the country. The objectives were to feedback and discuss the appraisal findings and to begin the process of learning skills in working with distressed and vulnerable children. Khana will continue this basic skills building as a part of routine and long-term technical support to NGO partners.

Khana will also support NGO partners to conduct participatory reviews of their current projects with their communities, and assist them to work with key stakeholders in their area to reformulate their projects according to expressed need. Needs and resources for children affected by AIDS will therefore be appraised again in each NGO area of operation. Not only will this add to the body of knowledge Khana is accumulating, it will also result in at least some communities working with the NGOs to integrate appropriate responses for children into their on-going HIV/AIDS prevention and care work.

It is anticipated that re-designed NGO partner projects will begin implementation in August 2000. At this stage, with support from the Alliance, Khana plans a six month project to assist some NGOs and their communities to develop and monitor appropriate indicators. This process will be documented as part of a larger project to explore the development of different models of integrating HIV/AIDS care into prevention work in rural communities.

Given available capacity and resources, it is not possible for Khana and its partners on their own to achieve widespread impact. Although individual communities, families and children themselves need to be central in decision making and implementation, there is a vital role for the government, UN agencies and other NGOs in upgrading skills and resources. The next logical step would be to carry out a systematic situation analysis and from this to develop and implement a national strategy for children affected by AIDS.

During 2000, Khana will therefore also undertake to disseminate the appraisal and other findings widely, and to advocate for a co-ordinated, multi-sectoral response the needs of children affected by AIDS in Cambodia.

APPENDICES 7

APPENDIX 1: DESCRIPTION OF APPRAISAL METHODS

Appraisal Design
Feb/March 2000

1. Introduction

An appraisal of needs and resources for children affected by AIDS was planned by the Khmer HIV/AIDS NGO Alliance (Khana) and its NGO partners. The aim of the appraisal was to explore the potential for integrating services which can benefit children affected by AIDS, into ongoing NGO work in HIV prevention and care. Since there has been little previous exploration of the needs and resources for children affected by AIDS in Cambodia it was anticipated that the appraisal would raise more questions than it answered. It was intended that findings would act as a catalyst for further exploration by Khana partners (participatory project reviews in May 2000) and hopefully by other interested organisations.

2. Appraisal Objectives

The objectives of the appraisal were to work with a wide range of individuals and organisations to:

- Determine vulnerability/resilience factors for children
- Explore how HIV/AIDS-related life events impact on these factors
- Identify the range of needs specific to children affected by AIDS
- Identify existing resources which could or do address these needs
- Identify barriers to addressing these needs
- Suggest strategies to fill existing gaps in service provision

3. Appraisal Process

The appraisal was carried out by Khana staff and NGO partners with technical support from the AIDS Alliance. Individuals from 12 Khana NGO partners from 10 provinces facilitated the appraisal (see table 1). After a five-day planning workshop to enhance skills in appraisal facilitation, facilitators were divided into 6 teams of 3 people each. Each team spent 10 days working with individuals and organisations in either a rural or urban area, and also in the provincial town of that area. This was followed by a two-day feedback workshop to develop a framework for reporting the appraisal. Khana drafted a preliminary report, which was circulated for verification. The report then formed the basis of two workshops for Khana partner NGOs on "integrating services for children affected by AIDS into on-going HIV prevention and care projects". These workshops were intended to broaden NGOs knowledge of the issues faced by children affected by AIDS and inform their subsequent process of review and project re-design.

4. Appraisal Locations

The appraisal was carried out in Phnom Penh, Battambang, Kratie, Kompong Thom and Prey Veng. Provinces were chosen because they have:

- Different levels of INGO/UN agency activity with children
- Different levels of Khana partner activity
- Different risk factors including migration
- High priority in the National HIV/AIDS Strategy

5. Appraisal Methods

Because there has been little previous work carried out in Cambodia on the needs of children affected by AIDS, it was difficult to know exactly which questions need to be answered. For this reason, the appraisal was carried out with the use of open-ended participatory tools and techniques[30]. These tools

30 *Janet Harris, Chris Ellwood, Rosaline Barbour and Tilly Sellers. "Health-related knowledge and perceptions: Putting research into context for Belfast" Report for Belfast Health Authority, June 1996.*

are highly visual and enabled participants with different levels of literacy and verbal skills to participate in the appraisal[31]. They also enable people to communicate more easily about sensitive or personal issues, and reduce the risk of personal disclosure.

Three main tools were adapted and pre-tested during a five day appraisal planning workshop - (i) vulnerability drawing and story, (ii) network diagram of AIDS-related life events and (iii) community support timeline (see table 2 for description of tools). The pre-testing was carried out with vulnerable children either in orphanage care (SFODA), in foster care (Bamboo Shoots Centre) or living on the street (FRIENDS). Facilitators asked follow up questions with reference to a general checklist of issues, which was developed during the appraisal planning workshop. Key points from the discussions were noted by each team and were attached to the flipchart sheets showing the outcome of the tools used during the session.

The tools were all intended to generate similar information from different perspectives, and therefore to provide a measure of triangulation. Participant observation was also used by the teams to supplement their findings.

Where it was difficult for participants to use these visual tools due to a lack of space or time, the checklist provided the basis for conducting a semi-structured interview.

Appraisal findings were supplemented by information from national and international sources, and by an analysis of six months worth of quantitative data related to children affected by AIDS which was collected by Khana partners.

6. Appraisal Issues

Following a preliminary literature review of experiences addressing the needs of children affected by AIDS in other countries, it was anticipated that the checklist would prompt for needs in the following types of areas, although would not be restricted to these areas:

31 *Robert Chambers."Whose Reality Counts? Putting the first last" IT Publications, 1997*

Lower income, increased expenses	Malnutrition
Indebtedness	Increased susceptibility to illnesses
Loss of property (e.g. jewellery, land)	Less medical care
Increased household work & responsibility	Less food
Less money for medicine and sundries	Disruption of education/life skills education
Deterioration of house/shelter	Less care/nurturing by parents
Increased violence/impatience by parents	Stress/Depression/Shame/Anger of parents Stress, depression,
shame, confusion of children	Increased domestic violence
Ostracism/Isolation by relatives	Ostracism/Isolation by friends
Weaker/Lose contact with relatives & friends	Ostracism/isolation by neighbours
Weaker/Lose contact with neighbours	Forced into bonded labour, sex work
Exposed to anti-social influence/behaviour	Weakening of values due to exposure
Poverty of relatives/potential foster families	Lack of infrastructure/facilities

Similarly, the types of resources to be probed during the appraisal may include, but would not be restricted to the following:

Employment/Income generation & savings/credit programmes	Community education-solidarity strengthening programmes
Community mutual support programmes	Strengthening of values and civic education
Advocacy to improve laws related to credit/pawn, land and child labour	Advocacy for improving access to basic services
Strengthening agriculture/fishery development programmes	Life skills programmes for children and youth
Family counselling/crisis intervention programmes	Sexual health improvement programmes for youth
PWA Group/Inter-family support programmes	Primary health care education including nutrition

7. Appraisal Participants

During the appraisal-planning workshop, each team made a detailed plan to decide who should be involved in the appraisal in each area. This included representatives from UN agencies, INGOs, NGOs, GOs (particularly from MoH, MoWVA, MoSA and MoRD), at national, provincial and district levels. It also included key informants at community level (leaders, elders, monks, teachers, CBOs, Women's organisations etc), PLWHA support groups, families affected by AIDS and vulnerable/orphaned children in different situations. Each team carried out between 15 and 30 appraisal sessions both with groups and with individuals in a variety of settings - in villages, district and provincial capitals. Facilitators asked

'who should we talk to next' at the end of each appraisal session in order to identify new organisations/groups and in order to verify their existing plan.

At the end of each day the teams conducted a review of findings and targeted where there were gaps either in types of participant, or types of issues.

At the end of the appraisal, approximately 60 people from 40 NGO, government and UN agencies attended a verification meeting in Phnom Penh. This was held to check out the validity of the main findings and to get people together to begin discussing first hand issues relating to children.

Ethical Considerations

Although Khana has good contacts in the appraisal areas who were able to provide follow-up services if requested by appraisal participants, certain measures were taken to reduce the likelihood of the appraisal negatively impacting on vulnerable participants - particularly children.

- Appraisal facilitators were selected because of their experience both in the use of participatory tools, and in working with vulnerable groups (PLWHA and affected families, vulnerable youth and children).
- All facilitators were given a letter to identify them and given details about the aims of the appraisal.
- Facilitators were trained not to raise expectations, but to be realistic about the possible impact of the appraisal.
- Facilitators worked as a team, not on their own.
- All participants were able to choose whether or not they wished to participate after being given details of the aims of the appraisal and about what would happen to the information.
- An informal contract regarding time etc. was made with participants before the session begins.
- The visual/participatory tools used enabled participants to control their own level of participation and reduced the need for personal disclosure.
- Where possible participants worked in groups to maximise discussion and further reduce the possibility of disclosure.
- Permission was requested to 'take' information from the session (diagrams, drawings, notes etc.

- Names and contacts were only asked of people working for organisations.
- Appraisal facilitators carefully observed participants' comfort levels during each session and reacted accordingly.
- Participants were asked if they would like to verify information in the draft report

Table 1 Appraisal Facilitators

Name	Organisation	Appraisal Team
Im Loum	Huripruda (battambang)	1-Battambang
Kov Pisey	AFD (Takeo)	1-Battambang
Kong Samnang	SEADO (Banteay Meanchey)	1-Battambang
Oum Chantha	CCASVA (Prey Veng)	2-Prey Veng
Phok Bunroeun	CCASVA (Phnom Penh)	2-Prey Veng
Man Savann	Kasekor Thmey (Kg.Cham)	2-Prey Veng
Prum Ny	MODE (Kg. Thom)	3-Kompong Thom
Uch Sakun	MODE (Kg. Thom)	3-Kompong Thom
Leng Sothear	CDRCP (Kg. Thom)	3-Kompong Thom
Yous Thy	KWWA (Kratie)	4-Kratie
Y Srey Neang	KWWA (Kratie)	4-Kratie
Ros Monichoth	KBA (Banteay Meanchey)	4-Kratie
Sam Sopheak	IDA HCT 1 (Phnom Penh)	5-Phnom Penh
Soeun Sotheany	IDA HCT 2 (Phnom Penh)	5-Phnom Penh
Um Sophan	Rachana (Takeo)	5-Phnom Penh
Prang chanthy	Khana	6-Phnom Penh
Lychan Sophal	Khana	6-Phnom Penh
Ang Chamrourn	NAPA (Kg. Speu)	6-Phnom Penh

Alliance technical support was provided by:

Tilly Sellers,

Alex Marcelino,

Henrietta Wells

Table 2: Description of appraisal Tools

Vulnerability drawing and story	Participants draw picture of 'vulnerable' child and 'non-vulnerable' child of different ages and make up a story about each one. Discussion about comparisons draws out vulnerability and resilience factors. Participants add HIV/AIDS to both stories. Discussion draws out impact of AIDS on vulnerability factors. Participants summarise by defining issues for CAA, what helps minimise the impact of AIDS for children and what hinders this process.
Network diagram of AIDS-related life events	Participants make a network diagram showing the links between different AIDS-related life events (father sick, mother diagnosed, father dies, mother dies etc.) and the impact of each event on the family. When the diagram was finished, participants indicate the action necessary to minimise negative impact on CAA at each of the network diagram nodes. Discussion draws out who could carry out the action and what was the most effective strategy to use in each case.
Community support timeline	Participants make timelines for boy/girl from 0-5, 5-10 and 10-15 yrs. On the timeline participants make drawings of 'who in the community was important to the child' at the different life stages. When the drawings were finished the participants discuss what relationship each of the drawings has with the child - what needs they help address. Participants were then asked to explain how the relationships would change at different life stages if the child's mother/father become sick and die of AIDS. Discussion draws out changing/additional needs of CAA, and who in the community would respond to these needs.

APPENDIX 2A: LIST OF NGO, UN AND GOVERNMENT AGENCIES PARTICIPATING

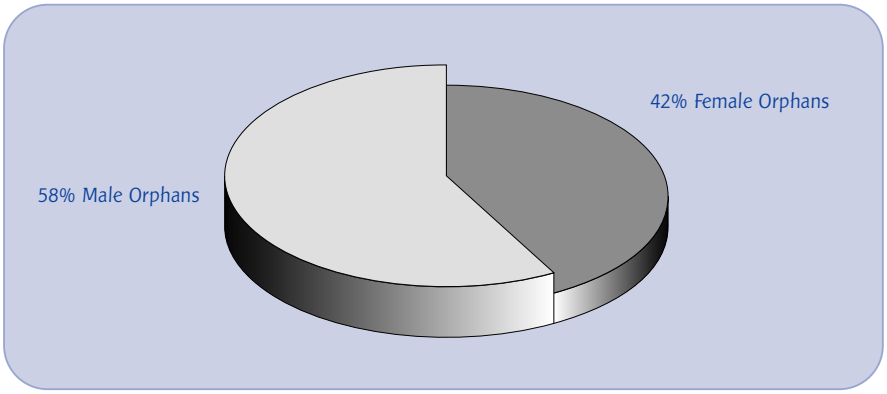
Acleda	Phnom Penh
AFD	Takeo
AS	Battambang
ASPERA	Phnom Penh
Cambokids	Phnom Penh
Caram CARE	Phnom Penh
Carere	Battambang
Carritas	Kg. Thom
CCASVA	Phnom Penh
CCASVA	Prey Veng
CDRCP	Kampot
Center of HOPE	Phnom Penh
CHED	Battambang
Church World Service	Kg. Thom
Community Aid Abroad	Kratie
Concern World Wide	Phnom Penh
CORD	Prey Veng
CPCR	Phnom Penh
CRC	Phnom Penh
CWDA	Phnom Penh
District Government	Kratie, Battambang, Kg Thom, Prey Veng
Donbosco	Phnom Penh
EDAT	Battambang
Enfants du Cambodge	Phnom Penh
EU STD Project	Phnom Penh
FHI	Phnom Penh
Friends	Phnom Penh
GTZ	Phnom Penh
Gout d'Eau	Prey Veng; Poipet
Handicap	Kg. Thom
Harvest International	Phnom Penh
Health Net International	Kratie
Helpage International	Phnom Penh
HOPE Cambodia	Phnom Penh
Huripruda	Battambang
IDA	Phnom Penh
International Child Care	Kg. Thom
IOM	Phnom Penh
KADOC	Kratie
Kasekor Thmey	Kg. Cham
KBA	Banteay Meanchey
KNCED	Battambang
Krousatmey	Phnom Penh
KT	Battambang
KWWA	Kratie
LICADHO	Phnom Penh
Maryknoll	Phnom Penh
Maternal and Child Health Department	Phnom Penh
MEDICAM	Phnom Penh
Ministry of Defence	Phnom Penh
Ministry of Education	Phnom Penh and Provinces
Ministry of Health	Phnom Penh and Provinces

Ministry of Rural Development	Phnom Penh and Provinces
Ministry of Social Affairs	Phnom Penh and Provinces
Ministry of Womens and Veterans Affairs	Phnom Penh and Provinces
MODE	Kg. Thom
MSF	Phnom Penh
Municipal Government	Phnom Penh
NAA	Phnom Penh
NAPA	Kg. Speu
National Institute of Public Health	Phnom Penh
National Paediatric Hospital	Phnom Penh
NCDP	Phnom Penh
NCHADS	Phnom Penh
Nutrition Centre	Phnom Penh
OXFAM UK	Phnom Penh
PFD	Kratie
Ponleu Chivit	Phnom Penh
PRASAC	Prey Veng
PRESS	Kg. Thom
Provincial AIDS Committee	Kratie
Provincial AIDS Committee	Battambang
PTD	Battambang
QSA	Phnom Penh
Rachana	Takeo
Reddbarna	Phnom Penh
Russian Hospital	Phnom Penh
SABORAS	Battambang
SCARO	Phnom Penh
SCC	Phnom Penh
SCF Australia	Phnom Penh
SCF UK	Kratie
SCF UK	Phnom Penh
SEADO	Banteay Meanchey
SFODA	Phnom Penh
SOS	Phnom Penh
SSC	Phnom Penh
Tabitha	Phnom Penh
TPO	Phnom Penh
UNAIDS	Phnom Penh
UNCHR	Phnom Penh
UNDP Carere	Phnom Penh
UNFPA	Phnom Penh
UNICEF	Phnom Penh
UNICEF	Kg. Thom
Vigilance	Kratie
Vithei Chivit	Phnom Penh
VSG	Battambang
WHO	Phnom Penh
World Vision	Phnom Penh
World Vision	Kg. Thom
World Vision Bamboo Shoots Project	Phnom Penh
YWAM	Phnom Penh
YWAM	Kratie

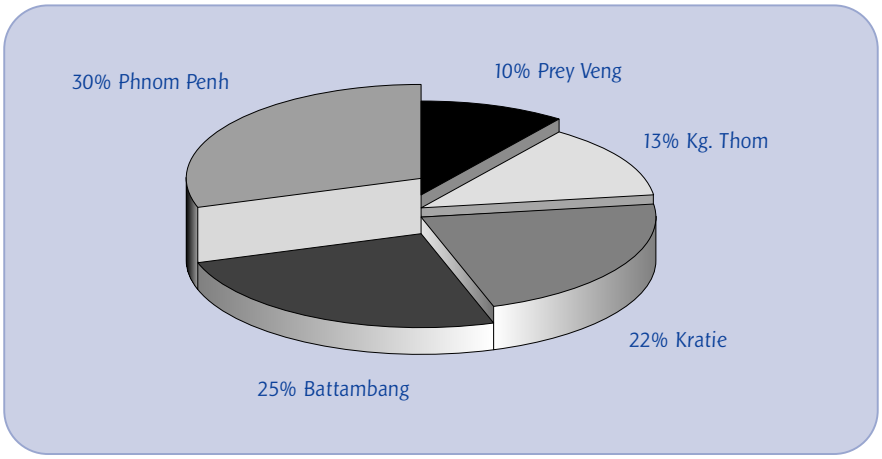
APPENDIX 2B: NUMBERS OF PARTICIPANTS

		Battambang		Prey Veng		Kg. Thom		Kratie		Phnom Penh	
	Total	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
Community (members, leaders and workers)	**121**	15	9	20	13	3	13		48		
Families Affected by AIDS	**67**			1	8			8	20	17	13
Traditional Healers	**5**			1	3	1					
Monks	**46**	1		6		26	3	10			
Government Staff`	**54**	4	2	6	3	10	3	7	5	5	9
NGO, UN Staff	**127**	4	5	3	4	6	4	13	13	42	33
School Children	**85**	38	38	5	4						
Orphans (community, orphanage and street)	**413**	71	46	8	7	33	19	37	40	91	61
Total	**918**	**133**	**100**	**50**	**42**	**79**	**42**	**75**	**126**	**155**	**116**

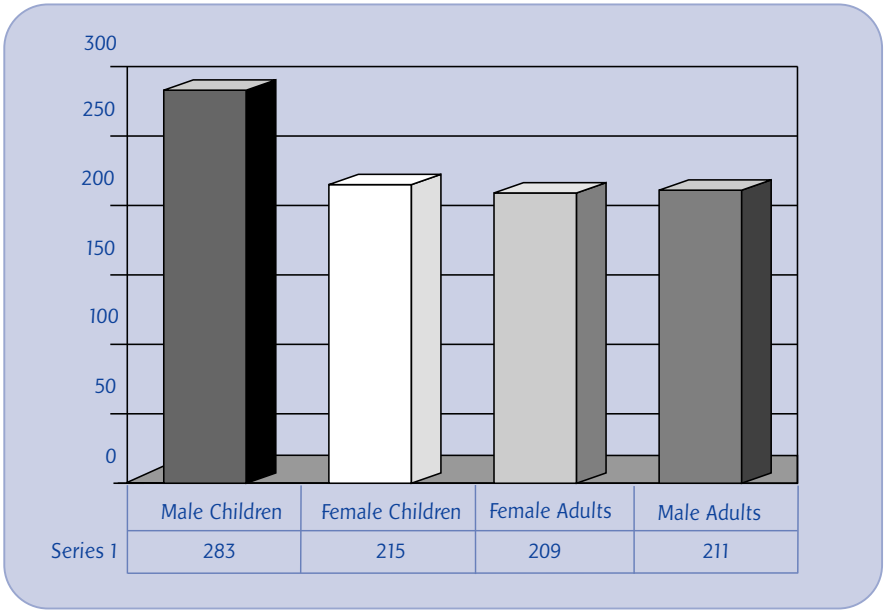
Orphaned Participants



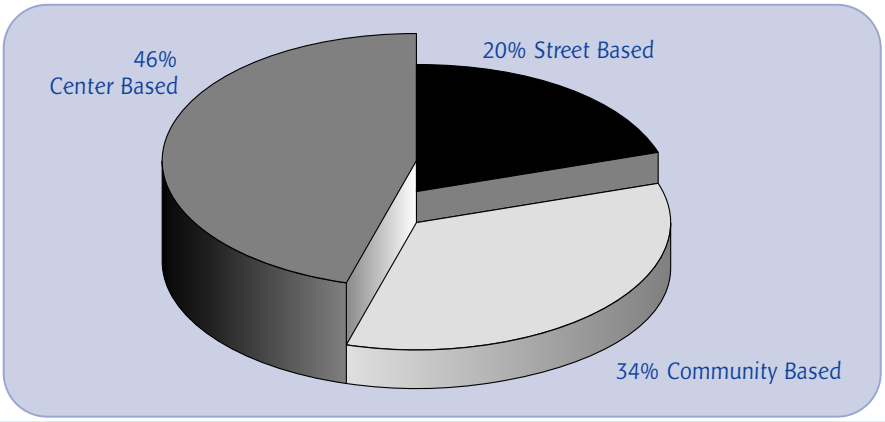
Appraisal Participants



Appraisal Participants



Orphaned Participants



APPENDIX 3: TEXTS AVAILABLE AT KHANA

AHRTAG. "Caring with Confidence: Practical information for health workers who prevent and treat HIV infection in children". Briefing Paper

APCASO. "Report of the Consultative Phase of the APCASO HIV/AIDS and Human Rights Project in Cambodia" 2000

Ayieka, By. "From Single Parents to Child-Headed Households: The Case of Children Orphaned by AIDS in Kisumu and Siaya Districts" UNDP Study Paper No. 7

Boonchalaksi, Wathinee and Guest, Philip, "AIDS and Children: Prospects for the year 2000" 1993 Institute for Population and Social Research, Mahidol University, Thailand.

Cambodian Ministry of Women's and Veterans' Affairs. "Workshop Report of the National Workshop on Women and AIDS in Cambodia, December 1999"

De Lay, Brigette. "Participatory Action Research for the Rights of the Child". IRC Training Manual for developing and designing participatory, rights-based children's programs.

Donahue, Jill. Williamson, John. "Children and Families Affected by HIV/AIDS: A Review of the COPE Program in Malawi for the Displaced Children and Orphans Fund" 1996

Donahue, Jill. Williamson, John. "Community Mobilization to Address the Impacts of AIDS: A Review of the COPE II Program in Malawi for the Displaced Children and Orphans Fund" 1998

Donahue, Jill. "HIV/AIDS & Economic Strengthening via Microfinance". DCOF 2000

Foster, Geoff. Choice, Makufa. "Community Mobilisation Best Practices. The Families, Orphans and Children Under Stress (FOCUS) Programme" 1998

Francois-Xavier Bagnoud US Foundation. "AIDS Orphans: Towards an action plan for going to scale" Interagency Meeting on Children Affected by HIV/AIDS. 2000

HelpAge International. "Summary Report on The Situation of Older People in

Cambodia" 1998 Report with the Cambodian Ministry of Social Affairs, Labour and Veterans Affairs

Hunter, Susan. Williamson, John. "Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS" Report for USAID 1999

IICW. "A Positive Woman's Survival Kit"

International HIV/AIDS Alliance. "OVC in Burkina Faso: First Steps in Community Mobilisation" 2000

International HIV/AIDS Alliance. "Building Partnerships: Sustaining and expanding community action on HIV/AIDS" 1999

International HIV/AIDS Alliance. "Report from the Annual Supporters Meeting" 2000

Janet Harris, Chris Ellwood, Rosaline Barbour and Tilly Sellers. "Health-related knowledge and perceptions: Putting research into context for Belfast" Report for Belfast Health Authority, June 1996.

Jerker Edstrom et al. "Ain't Misbehavin': beyond individual behaviour change" PLA Notes 37, IIED. February 2000

Kemmerer, Frances. "Incentives for Primary Teaching: Status and Issues". Report for Cambodian Ministry of Education, Youth and Sport, 1999

Kemmerer, Frances. "Resources for Schooling: A Model for Local Accountability". Report for Cambodian Ministry of Education, Youth and Sport, 1999

Lee, Tim et al. "Report of a participatory self-evaluation of the FACT Families Orphans and Children Under Stress (FOCUS) Programme" 1999

Lyons, Miriam. "The Impact of HIV and AIDS on Children, Families and Communities: Risks and Realities of Childhood during the HIV Epidemic" UNDP HIV and Development Programme Issues Paper No. 30

Meegan, Michael. Conroy, Ronan. Tomkins, Andrew. "Identifying emerging needs among AIDS orphans in Kenya". Presentation for the Annual Scientific Review, University of Nairobi, 2000

MMWR. "Public Health Service Guidelines for the Management of Health-Care Worker Exposures to HIV and Recommendations for Postexposure Prophylaxis" 1998

Robert Chambers. "Whose Reality Counts? Putting the first last" IT Publications, 1997

Save the Children. "Promoting psychosocial well-being among children affected by armed conflict and displacement" International Save the Children Alliance Working Group on Children affected by armed conflict and displacement. 1996

UNAIDS. "The HIV/AIDS/STD situation and the national response in the Kingdom of Cambodia" 2000

UNESCO. "Adolescence Education Newsletter" Vol. 2, No. 2. 1999

UNFPA. "Country Population Assessment: Cambodia" 2000

UNHCR Committee on the Rights of the Child. "Initial Report of States Parties: Cambodia" 1997

UNICEF "Children Orphaned by AIDS" 1999

USAID "Community Mobilization for Orphans in Zambia: An Assessment of the Orphans and Vulnerable Children Program of Project Concern International" 1999

USAID. "Community Mobilization for Orphans in Zambia: An Assessment of the Orphans and Vulnerable Children Program of Project Concern International" 1999

Wells, Henrietta "Combining Cambodian Resources in a Model of Home and Community Care for People with HIV/AIDS." Presentation to 4th International Conference on Home and Community Care for People with HIV/AIDS, Paris 1999.

Williamson, John. "Children and Families affected by HIV/AIDS- Guidelines for Action" (draft) 1995

Williamson, John. "Finding a Way Forward: Principles and Strategies for Intervention" (draft) 1999

Wright, Graham. "A Critical Review of Savings Services in Africa and Elsewhere" For MicroSave-Africa. 1999

APPENDIX 4: LATEST BIBLIOGRAPHY

SELECTED RESOURCE MATERIAL CONCERNING CHILDREN AND FAMILIES AFFECTED BY HIV/AIDS

John Williamson

(revised March 17, 2000)

General Material on AIDS-Affected Children and Families

Action for Children Affected by AIDS: Programme Profiles and Lessons Learned (Sue Armstrong and John Williamson) WHO and UNICEF, New York, December 1994, 119 pages.

Bor, Robert and Jonathan Elford, eds., The Family and HIV, Cassell, London and New York, 1994, 282 pages.

"*Children in a World With HIV/AIDS: New Challenges New Choices*", UNICEF, presentation to the UNICEF Executive Board, September 1998 (CD ROM. in PowerPoint, text by Susan Hunter)

"*Coping with the Impact of AIDS*" in *Confronting* AIDS: *Public Priorities in a Global Epidemic* (Mead Over and Martha Ainsworth) World Bank, Oxford Universtiy Press, 1997, pages 173-237.

Donahue, Jill, "*Community Mobilization and Microfinance Services as HIV/AIDS Mitigation Tools*", prepared for the Displaced Children and Orphans fund of USAID as a supplementary report to "Children Affected by HIV/AIDS in Kenya: An Overview of Issues and Action to Strengthen Community Care and Support", Displaced Children and Orphans Fund/USAID and UNICEF, 1999.

Donahue, Jill and John Williamson, "Community Mobilization to Mitigate the Impacts of HIV/AIDS, Displaced Children and Orphans Fund, September 1, 1999, 9 pages.

Donahue, Jill, Susan Hunter, Linda Sussman, and John Williamson, "Children Affected by HIV/AIDS in Kenya: An Overview of Issues and Action to Strengthen Community Care and Support", Displaced Children and Orphans Fund/USAID and UNICEF, 1999, 53 pages.

Drew, R.S, C. Makufa, and G. Foster, "Strategies for Providing Care and Support to Children Orphaned by AIDS", AIDS Care, vol. 10, supplement 1, 1998, pp. S9-S15.

Drew, RS, G. Foster, J. Chitima, "Poverty B A Major Constraint in the Community Care of Orphans: A Study from the North Nyanga District of Zimbabwe," SAfAIDS, June 1996, Vol. 4, No. 2., 3 pages.

Elmore-Meegan, Michael, Ronan Conroy, Andrew Tomkins, "AIDS Orphans Study," presentation at the Collaborative Symposium on AIDS research, January 1999, Nairobi Kenya (due for publication).

FAO, The Effects of HIV/AIDS on Farming Systems in Eastern Africa, FAO Farm Management and Production Economics Service, Rome, 1995, 173 pages.

Foster, Geoff and Choice Makufa, "Community Mobilization Best Practices: The Families, Orphans and Children Under Stress (FOCUS) Programme," Family AIDS Caring Trust, Mutare Zimbabwe, 8 pages.

Foster, Geoff; Choice Makufa, Roger Drew; Stanford Kambeu; and Kingstone Saurombe; "Supporting Children in Need Through a Community-based Orphan Visiting Programme," AIDS Care, 1996, vol. 8, no. 4, pp. 389-403.

Geballe, Shelly, Janice Gruendel and Warren Andiman, eds., Forgotten Children of the AIDS Epidemic, Yale University Press, New Haven and London, 1995, 283 pages.

Hunter, Susan, "Into the 21st Century: Designing Care and Protection Programmes for Children Affected by HIV/AIDS PowerPoint Slide Show and Country Programme Assessment Guide, "UNICEF, 1999, 23.9 MB on CD ROM.

Hunter, Susan, "Sectoral Assessment of the Impact of HIV/AIDS on Education: Initial Planning Guide," (draft) Ministry of Education, Kingdom of Swaziland, April 17, 1999, 25 pages.

Hunter, Susan and John Williamson, "Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS," prepared by the Health Technical Services Project for the United States Agency for International Development, December 1997, 56 pages. (As of September 1999 available at **http://www.dec.org** Both the executive summary and full version are available. Paper copies can also be ordered at that web address or from Development Experience Clearinghouse, 1611 N. Kent Street #200, Arlington, VA 22209, tel: (703) 351-4006 or fax: (703) 351-4039)

Hunter, Susan and John Williamson, "Responding to the Needs of Children Orphaned by HIV/AIDS, Discussion paper number 7, prepared by the Health Technical Services Project for the United States Agency for International Development, June 1998, 30 pages.

Lee, Tim, Shareck Kagoro, Shana Muzanya, Choice Makufa, Geoff Foster, Rebecca Gonyora, "FOCUS Evaluation Report 1999: Report of a Participatory, self-evaluation of the FACT Families, Orphans and Children Under Stress (FOCUS) Programme", September 1999, Family AIDS Caring Trust, 56 pages.

Levine, Carol. ed., *A Death in the Family: Orphans of the HIV Epidemic*, United Hospital Fund, 1993, New York, 157 pages.

McKerrow, Neil and A.E. Verbeek, "Models of Care for Children in Distress: The Current Status of Children in The KwaZulu-Natal Midlands and the Nature of the Community Response", Edndale Hospital, KwaZulu-Natal, 1995, 56 pages.

McKerrow, Neil, "Responses to Orphaned Children: A Review of the Current Situation in the Copperblet and Southern Provinces of Zambia", UNICEF Lusaka, Research Brief No. 3, December 1997, 4 pages.

Mutangadura, Gladys, Duduzile Mukurazita, and Helen Jackson, "A Review of Household and Community Responses to the HIV/AIDS Epidmeic in the Rural Area of Sub-Saharan Africa",

Nampanya-Serpell, Namposya "Children Orphaned by HIV/AIDS in Zambia: Risk Factors From Premature Parental Death and Policy Implications." Dissertation for the PhD degree in Policy Sciences, University of Maryland Baltimore County, Awarded 1998. This dissertation can be downloaded from the web at: **http://wwwlib.umi.com/dissertations**

UNAIDS, UNICEF, and the National Black Leadership Commission on AIDS, "Call to Action for 'Children Left Behind' by AIDS", December 1, 1999, 4 pages.

UNAIDS Best Practice Collection, June 1999, 67 pages (on August 5, 1999, available at: **http://www.unaids.org/highband/bpc/keymaterials/impactagri/una99e39.pdf**).
Urassa, Mark; Ties Boerma, J; Ng'weshemia, Japheth; Isingo, Raphael; Schapink, Dick and Kumogola, Yusufu, "Orphanhood, child fostering and the AIDS epidemic in rural Tanzania" Health Transition Review, Supplement 2 to Volume 7, 1997.

Mutangadura, Gladys, and Helen Jackson, "HIV/AIDS and the Young: Three Studies in Southern Africa, SafAIDS News, December 1998, vol. 6, No. 4, 6 pages.

Webb, Douglas, "Orphans in Zambia: Nature and Extent of Demographic Change", AIDS Analysis Africa (Southern Africa Edition), 1995, Vol. 6, No. 2., pp 5-6.

Webb, Douglas, Geoff Foster, Hugo Kamya, Namposya Serpell, "Children Affected by HIV/AIDS: Priority Areas for Future Research," (draft) 1998, 8 pages.

Williamson, John, *Children and Families Affected by HIV/AIDS* : Guidelines for Action, (draft prepared for UNICEF to be revised and updated 1999, available in draft), October 1995, 120 pages.

Williamson, John, "Finding a Way forward: Prinicples and Strategies for Intervention", Draft, November 2, 1999. Available at: **http://www.iaen.org/impact/williamson.pdf**

Williamson, John and Jill Donahue, "Developing Interventions to Benefit Children and Families Affected by HIV/AIDS: a Review of the COPE Program in Malawi for the Displaced Children and Orphans Fund", 1996, 50 pages.

Williamson, John and Jill Donahue, "Community Mobilization to Address the Impacts of AIDS: A Review of the COPE II Program in Malawi, January 17-30, 1998", prepared by the Displaced Children and Orphans Fund of and War Victims Fund Project for USAID, June 1998, 44 pages.

World Bank, Confronting AIDS: *Public Priorities in a Global Epidemic* (Mead Over and Martha Ainsworth) Oxford University Press, 1997, pages 173-237.

Papers from the, Southern African Conference, "Raising the Orphan Generation, "organized by CINDI in Pietermaritzburg, 9B12 June 1998 and available (as of August 4, 1999) at: **http://www.togan.co.za/cindi/**

Available from UNDP HIV and Development Programme (as of August 5, 1999) **at: http://www.undp.org/hiv/studylis.htm**

From Single Parents to Child-Headed Households: The Case of Children Orphaned by AIDS in Kisumu and Siaya Districts, 1998
Also available from UNDP at: **http://www.undp.org/hiv/issuesli.htm**

Children in Families Affected by the HIV Epidemic: A Strategic Approach, Issues Paper # 13 (also available in French) by Elizabeth Reid

Links to resource material on children orphaned by AIDS are included on the web site of the Francois-Xavier Bagnoud Association at: **http://www.fxb.org/orphinfo.html#resources**

Bibliographies

HIV/AIDS Bibliography: An Annotated Review of Research on HIV/AIDS in Zambia, UNICEF and National AIDS/STD/TB and Leprosy Programme, 1996, (includes 10 listings on orphans, most unpublished)

A Selected Bibliography," Family AIDS Caring Trust, Mutare, Zimbabwe, 5 pages.

Situation Analyses and Assessments

"Family Coping and AIDS in Zimbabwe: A Study," Research Unit Series No. 4, Research Unit, School of Social Work, Harare, 1994, 72 pages.

"Final Report: Operational Research on the Situation of Orphans within Family and Community Contexts in Uganda," September - December 1993, Ministry of Labour and Social Affairs, Uganda Community-Based Association for Child Welfare, UNICEF Uganda, 128 pages.

Mutangadura, Gladys, Duduzile Mukurazita, and Helen Jackson, "A Review of Household and Community Responses to the HIV/AIDS Epidmeic in the Rural Area of Sub-Saharan Africa," UNAIDS Best Practice Collection, June 1999, 67 pages.

Paul Saoke and Roselyn Mutemi, "Needs Assessment of Children Orphaned by AIDS: Final Report," 1994, 58 pages.

Susan Hunter, "National Assessment of Families and Children Affected by AIDS," draft, Tanzania AIDS Project, August 1, 1994, 184 pages plus attachments. Webb, Douglas, "Children in Especially Difficult Circumstances (CEDC) in Zambia: A Situation Analysis," in SAfAIDS News, Vol. 4, No. 1, March 1996, pp. 2-6.

Socio-economic Impacts of HIV/AIDS and Responses

"Coping with the Impact of AIDS, in Confronting AIDS: Public Priorities in a Global Epidemic, The World Bank, Oxford University press, 1997, 65 pages.

Donahue, Jill, "Community-based Economic Support for Households Affected by HIV/AIDS", prepared by the Health Technical Services Project for the United States Agency for International Development, June 1998, 31 pages.

Delroix, Sylvie et AgnËs Guillaume, Le Devenir de Familles AffectÈes par le SIDA: Une ...tude de Cas en CÙte-d'Ivoire , " chapitre 17 dans Pion, Marc, Thèrése Locoh, ...milien Vignikin and Patrice, Vimard, "Mènages et Familles en Afrique: Approches des Dynamiques Contemporaines , " Les Dossiers du CEPED no 15, 1997, pp. 345-369.

Intensifying Action Against HIV/AIDS in Africa: Responding to a Development Crisis, Africa Region, The World Bank, August 1999, 90 pages.

Wright, Graham A.N., Deborah Kasente, Germina Ssemogerere, and Leonard Mutesasira, "Vulnerablity, Risks, Asssets and Empowerment: The Impact of Microfinance on Poverty Alleviation , " Final report, March 1999, MicroSave-Africa, 56 pages.

[See also " Useful Material Not Specific to HIV/AIDS " below.]

SPECIFIC ISSUES

Law and Policy

Herb, A., "The New York State Standby Guardianship Law: A New Option for Terminally Ill Parents , " Levine, C. ed., Orphans of the HIV Epidemic, United Hospital Fund of New York, 1993, pp. 87-93.

Pinot, M., "Custody and Placement: The Legal Issues , " Levine, C. ed., Orphans of the HIV Epidemic, United Hospital Fund of New York, 1993, pp. 75-84.

"Policy Guidelines for the Care of Orphans in Malawi and Coordination of Assistance for Orphans , " Task Force on Orphans, Ministry of Women and Children Affairs and Community Services, Government of Malawi, July 1992, 9 pages.

"Property-grabbing: Why Zambia Needs Stronger Laws to Protect Widow's Rights , " AIDS Analysis Africa, Vol. 4, No. 4, July/August 1994, pp. 1&7.

Psychosocial Issues

Dane, B., "Mourning in Secret: How Youngsters Experience a Family Death from AIDS , " Levine, C. ed., "*Orphans of the HIV Epidemic,* " United Hospital Fund of New York, 1993, pp. 60-68.

Dudley, R., "All Alike but Each One Different: Orphans of the HIV Epidemic, " Levine, C. ed., *Orphans of the HIV Epidemic*, United Hospital Fund of New York, 1993, pp. 56-59.

Draimin, B., "Adolescents in Families with AIDS: Growing Up with Loss, " Levine, C. ed., Orphans of the HIV Epidemic, United Hospital Fund of New York, 1993, pp. 13-23. "How Children React When a Family Member Has AIDS, " [English and Spanish] a brochure produced by Beth Israel Medical Center in New York City.

Kamya, Hugo, "Bereavement Issues and Spirituality, "submitted for publication July, 1998, 23 pages.

Kamya, "Groupwork with Children from HIV/AIDS-Affected Families, " *Journal of HIV/AIDS Prevention & Education for Adolescents & Children,* Vol. 1(2) 1997, pp. 73-91.

McKelvy, L., "The Well Children in AIDS Families Project: A Hospital-based Program , " Levine, C. ed., *Orphans of the HIV Epidemic,* United Hospital Fund of New York, 1993, pp. 104-109.

Mayer, R., "When the Butterfly Dies: The Loss of a Parent to AIDS, " Levine, C. ed., Orphans of the HIV Epidemic, United Hospital Fund of New York, 1993, pp. 27-35.

Sampa-Kamwendo, Annie, Thomas Syamujaye and Jonathan Brakarsh, "Manual for Psychosocial Counselling , " Children in Need Network (CHIN), July 1998, 73 pages.

Siegel, K. and Gorey, E., "Childhood Bereavement Due to Parental Death from

Acquired Immunodeficiency Syndrome , " *Journal of Developmental and Behavioral Pediatrics,* supplement: "Priorities in Psychosocial Research in Pediatric HIV Infection, eds. Bauman, L. and Wiener, L., Vol. 15, No. 3. June 1994, pp. 66-69.

[See also " Useful Material Not Specific to HIV/AIDS " below.]

Guidelines

Because You Love Them: A Parent's Planning Guide, Child Welfare League of America, 1994, 74 pages.

Newsletters

PCI Orphans and Vulnerable Children Programme Update, Project Concern International Zambia (e-mail: concern"amnet.zm)

Videos

Everyone's Child, produced in Zimbabwe by Media for Development Trust, 1996, 90 minutes. There is also a 20 minute training video drawn from the film with written material. Available from DSR dsr@us.net **http://www.catalog.com/dsr/film.htm**

The Orphan Generation, produced by Small World Productions, 10 and 40 minute segments. Can be ordered through UNICEF web site: **http://www.unicef.org** Click on catalogues and follow the instructions regarding ordering forms. The Orphan Generation is not listed on the web site, but just fill in the title in the order form.

Useful Material Not Specific to HIV/AIDS

MkNelly, Barbara and Christopher Dunford, "Are Credit and Savings Services Effective Against Hunger and Malnutrition? -A Literature Review and Analysis , " Research Paper No. 1., Freedom from Hunger, February 1996, 51 pages.

Tolfree, David, Roofs and Roots: The Care of Separated Children in the Developing World, Arena, Ashgate Publishing, Harts, England, and Brookfield, Vermont, USA, Save the Children Fund (UK), 1995, 251 pages. Arena, Ashgate

Publishing Limited, Gower House, Croft Road, Aldershot, Hants GU11 3HR, England: Ashgate Publishing Co., Old Post Road, Bookfieid, VT 05036, USA tel: (802) 276-3162. (available through **http://www.amazon.com**)

"Promoting Psychosocial Well-being Among Children Affected by Armed conflict and Displacement: Principles and Approaches, " Working Paper N. 1, Working Group on Children Affected by Armed Conflict and Displacement, Save the Children Federation, 1996 (available from Save the Children, 54 Wilton Road, Westport CT 06880).

Tolfree, David, Restoring Playfulness: Different Approaches to Assisting Children who are Psychologically Affected by War or Displacement, Radda Barnen (Swedish Save the Children), 1996, 212 pages. (**http://www.childrightsbookshop.org/**)

Wright, Graham A.N., Deborah Kasente, Germina Ssemogerere and Leonard Mutesasira, "Vulnerability, Risks, Assets and Empowerment - The Impact of Microfinance on Poverty Alleviation, " Final Report, March 1999, MicroSave-Africa (funded by UNDP and DFID), 90 pages.

APPENDIX 5: RESPONSES IN OTHER COUNTRIES

Communication from John Williamson

Below are some thoughts on helping children affected by AIDS to stay in school and prepare to support themselves.

In many countries keeping children in school is one of the most frequently cited concerns among HIV/AIDS affected households. If the cumulative impact of the disease causes an increase in the national school dropout rate, more severely affected countries may have, on the one hand, greater difficulty replacing the more highly educated and skilled workers who are dying of HIV/AIDS and on the other, growing numbers of disaffected youth and young adults unable to support themselves adequately.

Paying school expenses can be a prohibitive financial burden for families affected by HIV/AIDS, and girls, on whom much of a community's future well-being will depend, are often forced to drop out before boys. When household funds for school are short or help with work is needed at home, girls are often made to drop out first. Undereducating girls, however, has damaging long term consequences for the society. Research in Africa has found that a 10% gain in female literacy resulted in a proportional drop in the infant mortality rate. In Kenya it was also found that, for every 1,000 girls completing an additional year of school, two maternal deaths and 45 infant deaths would be prevented. Initiatives to help HIV/AIDS affected children to stay in school should consider giving priority to girls.

Government fees are typically a small part of the expenses families face to send a child to school. Many schools are able to function only by charging their own fees, which can be substantial. Other expenses include uniforms, books, and supplies. The additional expenses and loss of cash income or agricultural labor that come with illness force families to redirect their financial resources. Children are often forced to drop out of school before they are orphaned, and school expenses may no longer be affordable when children have to leave school to care for ailing parents and take on adult work responsibilities.

Death of teachers due to HIV/AIDS is another serious problem many governments are facing in maintaining the quality and availability of education. In Zambia, for example, the mortality rate of teachers in Zambian schools is 4

percent per year, and between four and five teachers die each day. While not all of these deaths are caused by AIDS, the epidemic is the likely explanation of why the teachers' death rate is significantly higher than that of the adult population in general. A recent report indicated that in Swaziland, a smaller country than Zambia, three to four teachers are dying per day. In 1993, it was estimated that, due to HIV/AIDS, Swaziland would spend almost one and a half million U.S. dollars in 1996 to replace and retrain teachers.

A recent controlled study on the situation of children orphaned by HIV/AIDS carried out in four districts in western Kenya found that children, one or both of whose parents had died of HIV/AIDS, were significantly disadvantaged co pared to other children. The study included 646 children, one or both of whose parents had died of HIV/AIDS, and a matched control group of 1,239 children. Among children in the control group, 73 percent had both parents living and 27 percent had lost one or both parents from causes other than the epidemic. The study also found that 52 percent of the children orphaned by HIV/AIDS were not in school, compared to two percent of the control group. Among the children orphaned by HIV/AIDS, 56 percent of the girls and 47 percent of the boys were not in school. Also, school performance and health were poorer among the children orphaned by HIV/AIDS.

From national to community levels, there have been a variety of responses made to help orphans and other vulnerable children stay in school, but there are no easy answers to the resource deficits HIV/AIDS is causing. Providing scholarships is a direct and efficient solution, but the expense makes it difficult to sustain this activity as an escalating number of children drop out of school. Some ministries of education have waived school fees for orphans, which can help, but the resulting deficits in ministry and school budgets have to be made up from other sources.

Some organizations have provided supplies and equipment or constructed classrooms for schools prepared to accept orphans. Community schools are another approach. Some communities have started community schools to provide educational opportunities for children unable to afford the costs associated with regular schools. Such schools are less expensive per pupil than government schools, but communities face significant challenges to support them indefinitely.

Measures to improve household economic capacity, particularly where the participants are women, can be one of the most important and sustainable

ways to address problems of educational access. A recent evaluation of the Uganda Women's Finance Trust, a microfinance program, found that participants used income secured through the program to pay both educational and health expenses, "It is interesting and important to note that UWFT's services are allowing clients to make substantial investments in sending children to school and curative health care. Indeed, these (and particularly education) repeatedly emerge as the most valued results of access to credit."

Some Possible Responses

There is no one best way to help prevent HIV/AIDS affected children from dropping out of school. Such action must respond to the specific pressures they face. Some have difficulty paying for fees, uniforms, books and supplies. In many households children's labor is needed at home to care for a sick parent, do household or agricultural work or earn money. Another factor that effects how much families are willing to sacrifice to keep children in school is the extent that they see education as a worthwhile investment of time and resources. Stigma and discrimination have also prevented some children from staying in school.

One of the most important things that governments can do is allocate the resources necessary to make at least primary education free. Growing donor interest in mitigating the impacts of AIDS, may help make this option more feasible.

- Paying School Expenses -- Where the barrier to staying in school is largely economic, perhaps the most common program activity has been to pay school or vocational training expenses for orphans, and sometimes other vulnerable children. This direct approach is effective but is difficult to extend to large numbers of children or to sustain.

- Collaborating with Schools -- Some NGOs have supported community efforts to repair or construct needed infrastructure in return for a commitment by the school to allow needy children to attend.

- Some orphans are not in school simply because their guardians do not send them. Community groups concerned with orphans and vulnerable children in Zambia and Malawi have helped some children return to

school by persuading their guardians that these children need to be in school. Appeals by local religious groups, emphasis on traditional values and responsibilities, parenting skills classes, and sensitization to children's rights can help motivate some care providers to send children to school.

- Day care programmes can free older children and adolescents, particularly girls, who are otherwise expected to stay home to care for their younger siblings.

- Special Schools for Working Children -- Arranging halfday school hours for children who must work has been another approach.

- Education for Working Children -- Attending school is difficult for thousands of children who have to work to survive. Some community schools have been established that operate on a half day basis, allowing children who must work the time to do so. Machuma schools in Nairobi have also served as collection sites for the materials they sell for recycling.

- Increasing household income - In principle, one of the most sustainable ways to help a child to remain in school is to enable the household to increase its income. Effective programming of this type, however, is difficult and requires solid technical expertise. Microfinance services involving solidarity group savings and lending, when operated according to state-of-the-art sustainability principles, have enabled some hous holds to send their children school.

- Primary education curricula in some developing countries, particularly in rural areas, have been criticized as too academic and not sufficiently oriented toward the types of work students will actually do when they finish school. Where education is not seen as being of practical value families are not willing to make sacrifices to keep children in school. Children affected by HIV/AIDS, who need to be able to support the selves at an early stage, and many other students, can benefit when cu ricula are adjusted to include information and skills relevant to local vocational realties.

- Vocational training, either formal or nonformal, can be valuable, if it helps young people gain marketable skills. Technical market analysis in formation is needed to assess whether training in specific areas will likely lead to employment or self employment, and those experienced

with job placement can help identify the inputs and abilities that contribute to success. A ministry of labor or industry may be able to provide information on skills that are in demand. Provisions should also be made for those who complete training to obtain the basic tools and equipment they will need to seek employment. However, if placement of beneficiaries into an established training programme is being considered, find out first how successful recent graduates have been in obtaining jobs. If training simply imparts technical skills, but does not lead to employment, it not only consumes resources that might be put to better use, but also discourages participants who have invested their time and effort.

- Apprenticeships are another nonformal approach with both advantages and limitations. Because participants learn in the established work places of artisans, it is not necessary to establish special training facilities. Additional tools or equipment may have to be provided for an apprentice, but extra hands and tools serve as an incentive for an artisan to participate because they can mean increased production. Some apprentices are able to continue working for an artisan after completing their training. A learning advantage for apprentices is that they not only gain technical skills, but also they are exposed to the workplace environment where they can learn some of the management skills needed to run a business. This approach is limited, however, by the number of artisans willing to take on apprentices and the capacity of the market to absorb those who are trained.

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